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Author manuscript *Clin Trials*. Author manuscript; available in PMC 2024 March 08.

Published in final edited form as:

*Clin Trials.* 2024 February ; 21(1): 95–113. doi:10.1177/17407745231204813.

## What influences trust in and understanding of clinical trials? An analysis of information and communication technology use and online health behavior from the Health Information National Trends Survey

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## Abstract

**Background:** Using information and communication technologies (ICTs) to seek, discuss, and share health-related information influences people's trust and knowledge of several health practices. However, we know little about the associations between individuals' ICTs use and their perceptions of trust and knowledge of clinical trials. Examining these associations may lead to the identification of target audiences and channels for developing effective educational interventions and campaigns about clinical trials.

**Methods:** In this study, we analyzed HINTS (Health Information National Trends Survey) data to document perceptions of clinical trial-related knowledge and trust that were recently added as questions in this annual national survey of US adults. We also examined correlates of these clinical trial perceptions that included sociodemographic factors and individuals' use of ICTs to seek health information, discuss such information with their healthcare providers, and share the information in their network.

**Results:** More than 90% of participants had no or limited perceived knowledge about clinical trials. Knowledge was higher among those who seek or discuss health-related information online. Differences in perceived knowledge and trust emerged for some racial/ethnic subgroups and other demographic factors. Providers were considered the most trusted source of information (73.6%), followed by health organizations (19.4%) and social support (7.1%). Trust in health organizations compared to health providers was higher among those who used online resources to share health

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Declaration of conflicting interests

The Authors declare no conflict of interests.

information online with others. Trust in social support was significantly higher among those who used ICTs to communicate about health.

**Conclusions:** Based on these findings, we recommend developing online resources about clinical trials to be distributed through social media. These resources should facilitate a dialogue and be targeted to several groups considering their ICTs' use.

#### Keywords

Patient participation; clinical trial communication; HINTS; online health behavior; ICTs

## Introduction

Researchers involved in developing new medical treatments and procedures rely on clinical trials to compare the safety and efficacy of potential innovations with existing standards of care.<sup>1</sup> Successful clinical trials require accruing an adequate number of participants to meet enrollment targets, which can be either patients or healthy individuals, depending on the scope of the trial. Despite their importance, recruiting participants for clinical trials is very challenging for several reasons, and enrollment rates remain low.<sup>2, 3</sup> For example, despite a proliferation of clinical trials for cancer treatment, less than 10% of all cancer patients enroll in trials.<sup>4</sup> Several barriers may influence individuals' decision to participate in clinical trials including trial design features, participation costs, or travel distance to the research facility.<sup>5, 6</sup> Poor communication about clinical trials with potential participants has emerged as an additional critical barrier to enrollment.<sup>7, 8</sup> The Health Interview National Trends Survey (HINTS) is a nationwide study that has been administered annually or bi-annually in the US since 2003 and is designed to facilitate research into the relationships between communication practices and health-related knowledge and perceptions.<sup>9</sup> Several new survey items related to clinical trials were added to the 2020 HINTS, presenting a unique opportunity to explore the relationships between communication behaviors and clinical trial perceptions among a national US sample.<sup>10</sup>

#### Challenges of communicating about clinical trials

Several communication challenges contribute to individuals' negative reactions towards medical research.<sup>7, 8</sup> First, healthcare providers and clinical researchers rarely invite patients to join clinical trials.<sup>11</sup> They are reluctant to talk with patients about clinical trials for a variety of reasons including the intrinsic uncertainty of the research inquiry, the fear of damaging relationships with their patients, and implicit bias.<sup>12</sup> Many healthcare providers also lament limited time during medical appointments and a lack of resources available to support challenging discussions<sup>13, 14</sup> as reasons for limited conversations about joining clinical trials. Overall, patients are more likely to join clinical trials when their physicians openly discuss clinical trials.<sup>7, 15</sup> Beyond the critical role of doctor-patient communication in clinical trial recruitment and patients' understanding of clinical research, data indicates that many patients learn about clinical trials from other patients, as well as friends or family members.<sup>16, 17</sup>

Second, many information resources for patients are lengthy and complex to understand.<sup>18</sup> For example, the key take-aways from informed consent documents are understood by only 75% of individuals who are offered an opportunity to join clinical trials.<sup>19</sup> Some specific concepts such as placebo and randomization are complicated to understand and require communicators to simplify them by considering cultural adaptations<sup>20, 21</sup> and more engaging strategies to reach patients.<sup>22–25</sup>

Third, there are discrepancies in how clinical research has been experienced and discussed by individuals depending on their socio-demographic characteristics.<sup>12,26</sup> Individuals from historically underrepresented groups, such as African Americans, have suffered abuses in the past that still influence their perceptions and experiences with clinical research.<sup>26</sup> These groups also have specific individual and relational needs that should be considered with greater attention when engaging in clinical research related discussions.<sup>27–29</sup> Everyday discriminations and lack of representation are other barriers that affect such discussions.<sup>26</sup>

Finally, patient-specific factors should be taken into consideration when communicating about scientific discoveries and medical research. These include strategies to seek information and process messages. For example, Occa and Morgan have observed that individuals react differently to specific message formats depending on their levels of ability and motivation to process clinical trial related information.<sup>24</sup> Hillyer and colleagues interviewed cancer patients and discovered that about a quarter of participants in their sample did not know what clinical trials are.<sup>30</sup> Their study echoes the findings from other projects<sup>31</sup> in which patients showed limited scientific literacy and challenges in understanding clinical trial-related information. In addition to challenges in processing and understanding clinical research, several segments of the population also show a marked mistrust, the belief that someone would harm their health or, more generally, would not act in their best interest, towards participating in clinical trials.<sup>28,32</sup> Mistrust can be directed towards healthcare institutions in general, like hospitals, not-for-profit organizations, and governmental institutions, but also towards specific individuals involved in the research process, such as researchers, physicians, and clinical personnel.<sup>33,34</sup> Mistrust in clinical research needs to be addressed by improving individuals' perceptions of scientific institutions and researchers and increasing their knowledge and understanding of the nature of the clinical research process.<sup>33,35</sup> To do so, it is necessary to explore both the information resources that individuals trust when considering information about clinical research and what people think they know about clinical research. The source and resulting perceptions are likely to impact communication behaviors, including how individuals seek information, whether they discuss such information with their healthcare providers, and whether and how they share the information in their network.<sup>36–38</sup> In this regard, special attention needs to be paid to the channels and resources used by individuals to seek health information.

#### Influence of information and communication technologies

Information and communication technologies (ICT), such as phones and computers, applications, online resources, and social media, are key vehicles for individuals to retrieve health-related information and form opinions about health issues.<sup>39</sup> While there are no commonly agreed definitions of ICTs, researchers use the term to identify technologies,

platforms, and programs which can improve access, effectiveness, and quality of healthcare information and practices.<sup>40</sup> The availability of multiple social-media and technological platforms has resulted in more proactive health information seeking from sources other than healthcare providers.<sup>41</sup> People are also increasingly using social networks, blogs, virtual worlds, online games and a variety of text messaging platforms to communicate about their health and to make decisions about health in general<sup>42,43</sup> and clinical trials specifically.<sup>44</sup> The increased use of ICTs for healthcare purposes has been facilitated by the low cost of the Internet, continuous technological advancements, and the potential to customize the information retrieved to one's own level of knowledge and understanding.<sup>40, 42</sup> ICTs have allowed individuals to be exposed to a variety of information with more autonomy than ever before.<sup>42, 45</sup> Individuals rely on several cues to judge the credibility of online information,<sup>36</sup> and some use such information in discussions with their healthcare providers.<sup>38, 46</sup>

Although these technologies and new ways of communicating have improved access to health information, healthcare services, and providers, research focused on concerns with social media information has emerged. For example, individuals can struggle to identify reliable information due to the high volumes and dramatical tone of health risk messages online.<sup>47</sup> Individuals' understanding and opinions about health issues is also affected by the structure of social media platforms. Researchers have conceptualized the existence of 'echo-chambers' of like-minded individuals, which limit the consumption of diverse perspectives and information.<sup>48</sup> While these echo-chambers may be considered as target groups to address with dedicated communication efforts, it is also clear that creating interventions for highly polarized groups presents significant challenges, and without adequate understanding of the target audience, these interventions may also backfire in the long term.<sup>49</sup>

#### Rationale for the current study

Researchers and public health experts need to identify target audiences and channels for developing effective educational interventions and campaigns about clinical trials. To support these efforts, this study has two key objectives. First, it aims to measure differences in perceptions of trust and knowledge about clinical trials by sociodemographic factors. Second, it aims to examine how differences in trust and knowledge varied depending on whether individuals used information technologies or online resources to seek health information, discuss with their healthcare providers, and make health decisions.

## Methods

#### Data source

For this study, we analyzed data from the Health Information National Trends Survey 5 (HINTS 5) Cycle 4 (2020).<sup>9</sup> HINTS is administered by the National Cancer Institute and is a cross-sectional, nationwide survey of health communication and information among civilian, non-institutionalized U.S. adults aged at least 18 years. HINTS investigators utilize a probability design and recruit participants from across the US to produce a sample of individuals with diversity in racial/ethnic and sociodemographic characteristics.<sup>10</sup> HINTS data includes analysis weights to account for selection probabilities and adjusts for non-responsive households. HINTS 5 cycle 4 was fielded

between February and June 2020 and participants completed a self-administered mailed questionnaire in English or Spanish. The response rate for HINTS 5.4 was 37%, and a total of 3,865 respondents returned completed surveys.

#### Study outcomes and correlates

**Primary outcomes.**—This study includes two main outcomes. The first is perceived knowledge of clinical trials, which was measured with one item: "How would you describe your level of knowledge about clinical trials?". Response options included "I don't know anything about clinical trials", "I know a little bit about clinical trials", and "I know a lot about clinical trials".

The second outcome is health information source trust, assessed using one item: "Imagine you had a need to get information about clinical trials. Which of the following would you most trust as a source of information about clinical trials?". Response options included "My health care provider", "My family and friends", "Government health agencies", "Health organizations or groups", "Disease-specific patient support groups", and "Drug companies." For the purposes of the current analyses, we combined the responses of "Government health agencies" and "Health organizations or groups" into a single response which we labeled "Professional Health Organizations." The responses "my family and friends" and "disease-specific patient support groups" were also combined into a single response labeled "social support". We excluded "drug companies" from the analyses due to a small number of responses (n = 16, 0.4% of the sample).

Sociodemographic and information correlates.—Correlates were selected considering standard socio-demographic variables and a review of the existing literature on barriers to clinical trials and ICTs to support health communication.<sup>50</sup> Socio-demographic factors included gender, race/ethnicity, age, education, income, geographical location, and cancer history. Health communication measures were designed to assess whether individuals used ICTs to seek clinical trial-related information, discuss such information with their healthcare providers, and share information in their networks. Although these items did not specifically ask about the use of ICTs for healthcare research, prior research has demonstrated a relationship between these general communication constructs and several health-relevant behaviors.<sup>51,52</sup> Table 1 indicates the ICTs-related items used from the HINTS dataset which all have dichotomous yes or no response options: (a) used the internet to look for health-related information, (b) used emails to communicate with their healthcare providers, (c) used ICTs (tables or smartphones) to discuss or take decisions about their health, (d) visited a social networking site or used a social networking site to share healthrelated information, (e) watched health-related videos on YouTube, and (f) used the internet for social support.

#### Data analysis

All analyses were estimated using Complex Samples in SPSS Version 26<sup>53</sup> to incorporate analysis weights that correct for nonresponse and noncoverage biases. Prevalence estimates are percentages and corresponding 95% confidence estimates generated using the SPSS Complex Samples Crosstabs procedure. Associations were first examined with

unadjusted (bivariable) logistic regression models to identify whether there are independent relationships between each correlate and outcome. An additional adjusted (multivariable) model was conducted with all the correlates included as independent variables in the same model to account for potential collinearity in sociodemographic and information communication factors and to account for differing levels of missing data across individual variables. Nominal, 2-sided 5% significance levels were applied for generating confidence intervals. Data analysis for this project was approved by the University of Kentucky Medical Internal Review Board (IRB#67898).

## Results

#### **Participants**

Participants' non-weighted responses to correlates are presented in Table 2. Percentages of the largest race/ethnicity response categories are similar to 2020 US Census estimates: Non-Hispanic, White: 61.6% Census/61.1% HINTS; Hispanic: 18.7% Census/17.1% HINTS; Non-Hispanic, Black: 12.4% Census/13.8% HINTS; Non-Hispanic, Asian: 6.0% Census/ 4.6% HINTS. The majority of participants were female (57.9%) and 50 years of age or older (combined 68%). For socio-economic status-related variables, 43% of participants completed a Bachelor's Degree or higher and 34% reported an annual income of \$75,000 or higher.

#### Perceived knowledge of clinical trials: Unadjusted models

For the entire sample, 41.3% of participants indicated that they don't know anything about clinical trials, 49.3% perceived knowing a little, and 9.4% perceived knowing a lot about clinical trials (Table 3). In unadjusted models, non-significant differences were observed for knowledge based on gender, urban/rural, and cancer history. Differences in knowledge were observed for some racial/ethnic subgroup comparisons. Specifically, Hispanics were significantly less likely than non-Hispanic whites to report knowing a little (OR 0.54, 95% CI 0.37–0.79) or knowing a lot (OR 0.52, 95% CI 0.27–1.00) compared to don't know. Non-Hispanic Asians were significantly less likely than Whites to know a little compared to don't know (OR 0.52, 95% CI 0.33–0.82). Participants over 75 years old were significantly less likely than adults between 18 and 34 years old to report knowing a little (OR 0.62, 95% CI 0.43–0.89) or knowing a lot (OR 0.47, 95% CI 0.25–0.89) compared to don't know. Higher levels of education were associated with more knowledge compared to less than a high-school degree in several comparisons. Significant differences were found in comparing "know a little" and "don't know" with the two highest income levels (\$50,000-75,000 vs < \$20,000: OR 1.69, 95% CI 1.12–2.55; \$75,000+ vs < \$20,000: OR 1.76, 95% CI 1.25–2.47). Individuals in the highest income category were also significantly more likely to report "know a lot" compared to the reference category (\$75,000 + vs < \$20,000: OR 1.95, 95% CI 1.05-3.63).

In unadjusted analyses of health communication behaviors, knowledge was higher among those who used email to communicate with healthcare providers, used technology to discuss their health, used the internet to look for health-related information, visited social

#### Perceived knowledge of clinical trials: Adjusted models

As in the unadjusted models, non-significant differences were observed for perceptions of knowledge based on gender, urban/rural, and cancer history in adjusted analyses. Differences in knowledge among Hispanics were non-significant but Non-Hispanic Asians were significantly less likely than Whites to know a little (AOR 0.43, 95% CI 0.26–0.70) compared to don't know. Participants between 65–74 years old were significantly more likely than 18–34 years old to report knowing a little (AOR 1.99, 95% CI:1.30–3.04) compared to don't know. Several effects of education levels were no longer significant in adjusted models except among when comparing the highest and lowest education groups in both higher levels of knowledge (AOR 4.09, 95% CI 1.79–9.37; AOR 16.10, 95% CI 5.84–44.40). Two ICT variables were significantly associated with both higher levels of knowledge: the use of email to communicate with providers (AOR 1.66, 95% CI 1.18–2.34; AOR 2.47, 95% CI 1.55–3.92) and use of online forums and health groups (AOR 2.21 95% CI 1.41–3.46; AOR 2.56, 95% CI 1.31–5.00). Participants who watched health-related videos on YouTube were more likely to report knowing a lot about trials (AOR 1.90, 95% CI 1.22–2.97).

#### Most trusted source of health information regarding clinical trials: Unadjusted models

For the entire sample, 73.6% of participants indicated they most trusted providers, 19.4% indicated health organizations, and 7.1% indicated social support (Table 4). In unadjusted models, non-significant differences were observed for sources of trusted information based on gender, income, and cancer history. Hispanic participants were more likely to trust health organizations over providers (OR 1.58, 95% CI 1.07-2.35) compared to non-Hispanic White participants. Compared to participants between the ages of 18 and 34, participants aged 50-64 (OR 0.58, 95% CI 0.39-0.86), 65-74 (OR 0.57, 95% CI 0.39-0.85), and 75 and older (OR 0.51, 95% CI 0.27–0.94) were less likely to trust health organizations versus providers. Participants with some college education (OR 2.34, 95% CI 1.08-5.07), or a Bachelor's degree or higher (OR 2.56, 95% CI 1.20–5.49) were more likely to report trusting health care organizations vs providers compared to participants with less than a high school education. Some college education was also associated with higher trust in social support versus providers (OR 2.71, 95% CI 1.05–7.04). Participants in the highest income category were significantly more like to trust social support over providers (OR 3.23, 95% CI 1.70–6.11). Those with a history of cancer were less likely to trust social support over providers (OR 0.51, 95% CI 0.32–0.83). For the ICT variables, trust in health organizations compared to health providers was higher among those who used email to communicate with healthcare providers, used the internet to look for health-related information, watched health-related videos, and used health support internet group. Trust in social support was significantly lower than providers among those who used technology to help with provider discussions (OR 0.49, CI 95% 0.31-0.7). However, trust in social support was significantly higher than providers for those who used the internet to seek health information, visited a social network site to share health information, and used the internet for health videos.

#### Most trusted source of health information regarding clinical trials: Adjusted models

Findings were similar in adjusted models for gender, race/ethnicity, education, and urban/ rural status. However, age differences in trust of health organizations over providers became non-significant in adjusted models. Participants in the two highest income categories were significantly less likely to trust health organizations over providers (\$50,000–75,000 vs <\$20,000: OR 0.48, 95% CI 0.26–0.89; \$75,000+ vs <\$20,000: OR 0.44, 95% CI 0.23– 0.77). Differences in trust based on cancer history were non-significant. For ICT variables, both used the internet for health-related information and watched videos were associated with significantly more trust in health organizations compared to providers. In adjusted models, watching for health videos remained significantly associated with trust in social support over providers.

#### Discussion

#### Statement of principal findings

In this study, we used HINTS data to explore differences in perceptions of trust and knowledge about clinical trials in a sample of US adults. We also explored correlates of these perceptions that included sociodemographic factors and whether individuals used ICTs to seek health information, engage in discussions with their healthcare providers, or make health decisions. Several interesting findings emerged.

First, our findings suggest most U.S. adults perceive little to no knowledge about clinical trials, supporting the need to more systematically provide informational and educational resources for the general population about clinical trials and medical research. In addition, Hispanics and Asian respondents reported lower knowledge perceptions compared to non-Hispanic Whites. However, these observed differences for Hispanics were non-significant after adjusting for other sociodemographic and information behaviors. In line with previous research, <sup>54,55</sup> our results support the need to further document the informational needs of specific groups and the potential value of developing culturally-sensitive educational and informational resources.

A second important finding was that knowledge perceptions varied along with patients' general use of social media, online support groups, and YouTube to retrieve health-related information. Although HINTS survey questions did not specifically focus on social media use for retrieving clinical trial information, this finding extends existing literature suggesting that patients may be exposed to clinical trial related information when online and they may be actively looking for this information on social media and among peers, or among patients with similar experiences or conditions.<sup>44</sup> Therefore, it may be beneficial to identify and provide online resources and links that eligible patients can consult on their own before and after having been introduced to an opportunity to join a clinical trial or participate in a medical research study. Internet links and information may also need to be distributed through social media to facilitate patients in identifying available clinical trials through government websites and other official resources. These materials for online distribution should be designed to consider both the information needs of patients and the social dynamics happening online. In adjusted models, using email to communicate with

providers and engaging in online support groups related to health emerged as significant factors driving knowledge. This suggests including patient activation strategies as part of clinical trials enrollment efforts could lead to improvements in potential participants' clinical trials-related literacy. These strategies have been successful in improving psychological and behavioral outcomes of patients dealing with complex illnesses.<sup>58</sup>

A third finding concerned the role of trust in clinical trials sources of information and how trust varied considering social media use. It is promising that most participants indicated their provider was their most trusted source of information (73.6%). The remaining participants trusted either professional health organizations (19.4%) or social support (7.1%) which demonstrates the value of providers integrating messages from health organizations or government sources in their clinical trial communications and including patients' family or caregivers in clinical trial-related discussions. Using the internet to gather health information and watching health-related videos online were associated with greater trust in professional health organizations. Contrasted with growing concerns about the proliferation of inaccurate health information and increasing mistrust in the medical field, it is encouraging that professional health organizations appear to be trusted sources among those seeking health information online. There was little evidence of systematic differences in trust for other sociodemographic or communication factors. Given that trust is a significant component of a perceived source credibility<sup>57</sup> and that being credible is essential when communicating health information, it is imperative to continue examining how to build trustful relationships and online exchanges with patients when discussing clinical trials.

#### Strengths and limitations

This study contributes to the literature in several meaningful ways. First, it is one of the few studies examining associations between ICTs use and trust and knowledge of clinical trials. Second, it takes advantage of the most recent HINTS, a publicly available dataset that captures health and communication-related perceptions from individuals across the US. The distribution of race and ethnicity of HINTS participants in the current sample closely mirrors 2020 US Census results<sup>58</sup> which allowed us to also explore clinical trial perceptions in a diverse sample.

A few limitations should be taken into consideration when evaluating the implications from this study. First, we used cross-sectional data, which prevented us from examining causal inferences. Second, the existing HINTS measures capture an important but narrow range of ICTs. This range of ICTs behaviors is collected through simple categorical measures. This limits the opportunity to examine a detailed picture of ICTs use to communicate about clinical research and health. Third, self-reported data may be affected by reporting or recall bias. Fourth, some of the differences observed by groups may have been exacerbated by the Covid-19 crisis and should be consider with caution when the crisis would be resolved. Fifth, we examined associations between ICTs use and trust and knowledge of clinical trials. While this association represents useful information, it is important to specify that there were no specific questions in the HINTS survey that explicitly examined whether ICTs were used for healthcare research. Finally, missing data is present for each variable and outcome which means that although HINTS does provide a nation-wide sample of adults, results of

analysis with missing data are not truly representative of the US population and may not be directly comparable across analyses.

#### Implications for policy, practice, and research

These finding have implications for developing communication and education interventions to address some of the challenges and needs that emerged from this analysis of HINTS data. Such interventions should strive to provide informational and educational resources for the general population about clinical trials and medical research, especially targeting specific groups. Considering the important role of trust and online behaviors, healthcare professionals should focus on creating a dialogue rather than a top-down form of communication about clinical trials and participation in medical research. Links and information should be made available through social media to facilitate patients in identifying available clinical trials through governmental websites and other official channels. However, future studies should focus on identifying the best strategies to distribute such materials to reach patients and citizens in general more effectively. Our study suggests YouTube may be an important channel in efforts to recruit participants or communicate about medical research innovations. Future studies are needed to identify strategies to optimize communication on YouTube, and to explore its use in complementing other resources or social media outlets.

## Funding

This research was supported by pilot funding provided by the National Cancer Institute (NCI) through the University of Kentucky Markey Cancer Center's Cancer Center Support Grant (P30 CA177558). The study sponsor had no role in the conduct, review, or generation of this report. Content is solely the responsibility of the authors and does not necessarily represent the official views of the NCI.

## References

- 1. National Institutes of Health. The basics [Internet]. Bethesda (MD): National Institutes of Health, https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics (2022, accessed 20 February 2022).
- Pemberton VL, Evans F, Gulin J, et al. Performance and predictors of recruitment success in National Heart, Lung, and Blood Institute's cardiovascular clinical trials. Clin Trials 2018;15(5):444–451. [PubMed: 30084662]
- 3. Zahren C, Harvey S, Weekes L, et al. Clinical trials site recruitment optimisation: guidance from clinical trials: impact and quality. Clin Trials 2021;18(5):594–605. [PubMed: 34041937]
- 4. Unger JM, Vaidya R, Hershman DL, et al. Systematic review and meta-analysis of the magnitude of structural, clinical, and physician and patient barriers to cancer clinical trial participation. J Natl Cancer Inst 2019;111(3):245–255. [PubMed: 30856272]
- Peay HL, Biesecker BB, Wilfond BS, et al. Barriers and facilitators to clinical trial participation among parents of children with pediatric neuromuscular disorders. Clin Trials 2018;15(2):139–148. [PubMed: 29475375]
- 6. McPhee NJ, Nightingale CE, Harris SJ, et al. Barriers and enablers to cancer clinical trial participation and initiatives to improve opportunities for rural cancer patients: A scoping review. Clin Trials 2022;19(4):464–476. [PubMed: 35586873]
- Albrecht TL, Eggly SS, Gleason ME, et al. Influence of clinical communication on patients' decision making on participation in clinical trials. J Clin Oncol 2008;26(16): 2666–2673. [PubMed: 18509178]

- 8. Morgan SE and Mouton A. Improving patient accrual to research studies and clinical trials through communication design interventions. In: Harrison TH and Williams E (eds) Organizations, Communication, and Health. New York: Routledge, 2015, pp. 106–124.
- National Institutes of Health. Survey instruments [Internet]. Bethesda (MD): National Cancer Institute, https://hints.cancer.gov/data/survey-instruments.aspx#H5C4 (2022, accessed 20 February 2022).
- Nelson D, Kreps G, Hesse B, et al. The health information national trends survey (HINTS): development, design, and dissemination. J Health Commun 2004;9(5):443–460. [PubMed: 15513791]
- 11. Occa A, Leip A, Merritt AS, et al. Prevalence and correlates of invitation to participate in clinical trials among US adults. Prev Med Rep 2022;26:101742. [PubMed: 35251912]
- 12. Hamel LM, Penner LA, Albrecht TL, et al. Barriers to clinical trial enrollment in racial and ethnic minority patients with cancer. Cancer Control 2016;23(4):327–337. [PubMed: 27842322]
- 13. ebron U, Honeyman C, Berhane M, et al. Barriers to obtaining informed consent on short-term surgical missions. Plast Reconstr Surg Glob Open 2020;8(5): e2823. [PubMed: 33133898]
- Rahman S, Majumder MAA, Shaban SF, et al. Physician participation in clinical research and trials: issues and approaches. Adv Med Educ Pract 2011; 2: 85–93. [PubMed: 23745079]
- Anderson A, Borfitz D and Getz K. Global public attitudes about clinical research and patient experiences with clinical trials. JAMA Netw Open 2018; 1(6): e182969–e182969. [PubMed: 30646218]
- Krieger JL. Family communication about cancer treatment decision making a description of the DECIDE typology. Ann Int Commun Assoc. 2014;38(1):279–305.
- Wicks P, Massagli M, Frost J, et al. Sharing health data for better outcomes on PatientsLikeMe. J Med Internet Res 2010;12(2):e19. [PubMed: 20542858]
- Wong LX, Bloom GM and Chee B. The Complex Maze of the Informed Consent Process: Helping to Improve Comprehension in Clinical Trial Participants with Alzheimer's Disease. J Alzheimers Dis Rep 2020;4(1):161–164. [PubMed: 32587949]
- Tam NT, Huy NT, Thoa LTB, et al. Participants' understanding of informed consent in clinical trials over three decades: systematic review and meta-analysis. Bull World Health Organ 2015;93:186–198H. [PubMed: 25883410]
- Krieger JL. Last resort or roll of the die? Exploring the role of metaphors in cancer clinical trials education among medically underserved populations. J Health Commun 2014;19(10):1161–1177. [PubMed: 23725021]
- 21. Krieger JL, Parrott R and Nussbaum JF. Metaphor use and health literacy: A pilot study of strategies to explain randomization in cancer clinical trials. J Health Commun 2010;16(1):3–16.
- 22. Flood-Grady E, Neil JM, Paige SR, et al. A pilot study determining comprehension and the acceptability of a cancer research study website for cancer patients and caregivers. J Cancer Educ 2020;35(3):589–598. [PubMed: 30847837]
- Neil JM, Gough A, Kee F, et al. The influence of patient identification and narrative transportation on intentions to participate in cancer research. J Cancer Educ 2019;34(4):725–734. [PubMed: 29721780]
- 24. Occa A and Morgan SE. Animations about clinical trial participation for cancer patients and survivors. J Health Commun 2019;24(10):749–760. [PubMed: 31543072]
- Peng W, Morgan SE, Mao B, et al. Ready to make a decision: a model of informational aids to improve informed participation in clinical trial research. J Health Commun 2019;24(12):865–877. [PubMed: 31663824]
- Bajaj SS and Stanford FC. Beyond Tuskegee—Vaccine distrust and everyday racism. N Engl J Med 2021; 384(5): e12. [PubMed: 33471971]
- Occa A, Morgan SE and Potter JE. Underrepresentation of Hispanics and other minorities in clinical trials: Recruiters' perspectives. J Racial Ethn Health Disparities 2018;5(2):322–332. [PubMed: 28452008]
- 28. Strekalova YA. When Trust Is Not Enough: A Serial Mediation Model Explaining the Effect of Race Identity, eHealth Information Efficacy, and Information Behavior on Intention to Participate in Clinical Research. Health Educ Behav 2018;45(6):1036–1042. [PubMed: 29478354]

- Herman PM, Larkey LK. Effects of an art-based curriculum on clinical trials attitudes and breast cancer prevention knowledge. Health Educ Behav 2006; 33(5):664–676. [PubMed: 16740503]
- Hillyer GC, Beauchemin M, Hershman DL, et al. Discordant attitudes and beliefs about cancer clinical trial participation between physicians, research staff, and cancer patients. Clin Trials 2020;17(2):184–194. [PubMed: 32009456]
- Fogel DB. Factors associated with clinical trials that fail and opportunities for improving the likelihood of success: a review. Contemp Clin Trials Commun 2018; 11: 156–164 [PubMed: 30112460]
- 32. Jaiswal J and Halkitis PN. Towards a more inclusive and dynamic understanding of medical mistrust informed by science. Behav Med 2019;45(2):79–85. [PubMed: 31343962]
- 33. Fisher JA. Institutional mistrust in the organization of pharmaceutical clinical trials. Med Health Care Philos 2008;11(4):403–413. [PubMed: 18633728]
- 34. Smirnoff M, Wilets I, Ragin DF, et al. A paradigm for understanding trust and mistrust in medical research: the Community VOICES study. AJOB Empir Bioeth 2018;9(1):39–47. [PubMed: 29368998]
- Frerichs L, Kim M, Dave G, et al. Stakeholder perspectives on creating and maintaining trust in community–academic research partnerships. Health Educ Behav 2017;44(1):182–191. [PubMed: 27230272]
- 36. Chang Y-S, Zhang Y and Gwizdka J. The effects of information source and eHealth literacy on consumer health information credibility evaluation behavior. Comput Human Behav 2021;115:106629.
- 37. Syn SY and Kim SU. The impact of source credibility on young adults' health information activities on Facebook: Preliminary findings. Proc Am Soc Inf Sci Technol 2013;50(1):1-4.
- 38. Waring ME, McManus DD, Amante DJ, et al. Online health information seeking by adults hospitalized for acute coronary syndromes: Who looks for information, and who discusses it with healthcare providers? Patient Educ Couns 2018;101(11):1973–1981. [PubMed: 30305253]
- Ihm J and Lee CJ. Toward more effective public health interventions during the COVID-19 pandemic: Suggesting audience segmentation based on social and media resources. Health Commun 2021;36(1):98–108. [PubMed: 33198528]
- 40. Aceto G, Persico V and Pescapé A. The role of Information and Communication Technologies in healthcare: taxonomies, perspectives, and challenges. J Netw Comput Appl 2018;107:125–154.
- 41. Jacobs W, Amuta AO and Jeon KC. Health information seeking in the digital age: An analysis of health information seeking behavior among US adults. Cogent Soc Sci 2017;3(1):1302785.
- 42. Macario E, Ednacot EM, Ullberg L, et al. The changing face and rapid pace of public health communication. J Commun Healthc 2011;4(2):145–150.
- Whitten P, Nazione S, Smith S, et al. An examination into audience targeting and the use of storytelling or statistical evidence on breast cancer websites. Patient Educ Couns 2011;85(2):e59– e64. [PubMed: 21306857]
- 44. Peng W, Occa A, McFarlane SJ, et al. A content analysis of the discussions about clinical trials on a cancer-dedicated online forum. J Health Commun 2019;24(12):912–922. [PubMed: 31709917]
- 45. Wellman B and Haythornthwaite C. The Internet in Everyday Life. John Wiley & Sons; 2008.
- 46. Benetoli A, Chen TF and Aslani P. How patients' use of social media impacts their interactions with healthcare professionals. Patient Educ Couns 2018;101(3):439–444. [PubMed: 28882545]
- Strekalova YA. Health risk information engagement and amplification on social media: News about an emerging pandemic on Facebook. Health Educ Behav 2017;44(2):332–339. [PubMed: 27413028]
- Cinelli M, Morales GDF, Galeazzi A, et al. The echo chamber effect on social media. Proc Natl Acad Sci 2021;118(9): e2023301118. [PubMed: 33622786]
- 49. Steglich C Why echo chambers form and network interventions fail: Selection outpaces influence in dynamic networks. arXiv preprint arXiv:1810.00211.
- Chou WYS and Budenz A. Considering emotion in COVID-19 vaccine communication: addressing vaccine hesitancy and fostering vaccine confidence. Health Commun 2020;35(14):1718–1722. [PubMed: 33124475]

- 51. Niu Z, Bhurosy T, Jeong DC, et al. Associations of social media use, patient-centered communication, and knowledge with perceived human papillomavirus vaccine effectiveness. Am J Health Behav 2020;44(5):642–651. [PubMed: 33121582]
- 52. Park HG, Kim YI, Huh WK, et al. The association between social media use for health-related information and compliance with breast and cervical cancer screenings. Res Rep 2020;4:e1–e14.
- 53. IBM Corp. IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp; 2019
- 54. Massett HA, Mitchell AK, Alley L, et al. Facilitators, challenges, and messaging strategies for Hispanic/Latino populations participating in Alzheimer's disease and related dementias clinical research: a literature review. J Alzheimers Dis 2021 Jan 1;82(1):107–127. [PubMed: 33998537]
- 55. Nolan TS, Bell AM, Chan YN, et al. Use of video education interventions to increase racial and ethnic diversity in cancer clinical trials: A systematic review. Worldviews Evid Based Nurs 2021;18(5):302–309. [PubMed: 34561957]
- 56. Mei-Yu LI, Wei-Shih WE, Apriliyasari RW, et al. Effects of patient activation intervention on chronic diseases: a meta-analysis. J Nurs Res 2020 Oct 1;28(5):e116. [PubMed: 32649394]
- 57. Mowen JC, Wien JL and Joag S. An information integration analysis of how trust and expertise combine to influence source credibility and persuasion. ACR North Am Adv. 1987.
- US Census Bureau. Race and Ethnicity in the United States: 2010 Census and 2020 Census, https://www.census.gov/library/visualizations/interactive/race-and-ethnicity-in-the-unitedstate-2010-and-2020-census.html (2021, accessed 13 July 2023).

### Table 1

Information and communication technologies-related items from the Health Interview Trends Survey

Behavior	HINTS Item Label	Item language					
Information seeking	B5a	In the past 12 months, have you used a computer, smartphone, or other electronic means to look for health or medical information for yourself?					
	B9b Has your tablet or smartphone helped you make a decision about how to treat an illness or condition?						
	B14a	In the last 12 months, have you used the Internet to visit a social networking site, such as Facebook or LinkedIn?					
	B14d	In the last 12 months, have you used the Internet to watch a health-related video on YouTube?					
Discuss with healthcare provider	B5b	In the past 12 months, have you used a computer, smartphone, or other electronic means to use emails to communicate with their healthcare providers?					
	B9c	Has your tablet or smartphone helped you in discussions with your health care provider?					
Share information	B14b	In the last 12 months, have you used the Internet to share health information on social networking sites, such as Facebook or Twitter?					
	B14c	In the last 12 months, have you used the Internet to participate in an online forum or support group for people with a similar health or medical issue?					

#### Table 2

Frequencies of outcomes, sociodemographic, and information and communication technologies-related survey questions from the Health Interview Trends Survey

Variable	Frequency <sup>a</sup>	Percentage
Clinical trial knowledge		
I don't know anything	1406	36.3
I know a little bit	1930	49.9
I know a lot	436	11.3
Missing/Non-response	93	2.4
Most trusted source of clinical trial information		
My health care provider	2686	69.5
Health organizations <sup>b</sup>	677	17.5
Social support <sup>C</sup>	248	6.4
Missing/Non-response	254	6.6
Gender		
Male	1487	38.5
Female	2052	53.1
Missing/Non-response	326	8.4
Race/Ethnicity		
Non-Hispanic White	2133	55.2
Non-Hispanic Black	481	12.4
Hispanic	596	15.4
Non-Hispanic Asian	161	4.2
Non-Hispanic Other	119	3.1
Missing/Non-response	375	9.7
Age		
18–34	484	12.5
35–49	703	18.2
50-64	1142	29.5
65–74	869	22.5
75+	540	14.0
Missing/Non-response	127	3.2
Education		
Less than HS	273	7.1
HS Grad	705	18.2
Some College	1081	28.0
Bachelor's Degree or Higher	1663	43.0
Missing/Non-response	143	3.7
Income		
< \$20,000	624	16.1
\$20,000-35,000	451	11.7

Variable	Frequency <sup>a</sup>	Percentag
\$35,000-50,000	460	11.
\$50,000-75,000	592	15.
\$75,000+	1321	34.
Missing/Non-response	417	10.
Urban-Rural		
Small town/rural	204	5.3
Micropolitan	274	7.
Metropolitan	3387	87.
Missing/Non-response	0	
Cancer History		
No	3168	82.
Yes	626	16.
Missing/Non-response	71	1.
Discuss with Healthcare Providers	•	
Emailed to communicate with healthcare providers		
No	1996	51.
Yes	1800	46.
Missing/Non-response	69	1.
Used a tablet or smartphone to help with discussions with health care provider		
No	1889	48.
Yes	1330	34.
Missing/Non-response	646	16.
Seek Health Information	•	
Use Internet to look for health-related information		
No	1151	29.
Yes	2677	69.
Missing/Non-response	37	1.
Used tablet or smartphone to make decisions about health		
No	1913	49.
Yes	1302	33.
Missing/Non-response	650	16.
Visited a social networking site e.g., Facebook		
No	1243	32.
Yes	2508	64.
Missing/Non-response	114	2.
Watch health-related videos on Youtube		
No	2340	60.
Yes	1388	35.
Missing/Non-response	137	3.
Use social network to share health-related info		
No	3243	83.

Variable	Frequency <sup>a</sup>	Percentage
Yes	483	12.5
Missing/Non-response	139	3.6
Use health-related online forum or support group		
No	3407	88.2
Yes	318	8.2
Missing/Non-response	140	3.6

<sup>a</sup>sample N = 3865

 ${}^{b}$  combined response options "government health agencies" and "health organizations"

<sup>c</sup> combined response options "my family and friends" and "disease support groups"

#### Table 3

Prevalence and correlates of perceptions of knowledge of clinical trials by demographics, health status, and health communication behaviors

	Prevalence <sup><i>a</i></sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Don't know anything	Know a little	Know a little compared to Don't know	Know a little compared to Don't know	Know a lot	Know a lot compared to Don't know	Know a lot compared to Don't know
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Entire Sample	41.3 (38.7, 44.0)	49.3 (46.8, 51.8)			9.4 (7.9, 11.1)		
Demographics							
Gender							
Male	41.9 (37.6, 46.3)	48.7 (44.7, 52.7)	Ref	Ref	9.5 (7.2, 12.4)	Ref	Ref
Female	39.8 (36.2, 43.5)	50.7 (47.3, 54.1)	1.10 (0.86, 1.40)	0.99 (0.74, 1.34)	9.5 (7.8, 11.4)	1.05 (0.71, 1.56)	1.20 (0.77, 1.88)
Race/Ethnicity							
Non-Hispanic White	36.7 (33.5, 40.1)	52.8 (49.6, 56.1)	Ref	Ref	10.4 (8.4, 12.9)	Ref	Ref
Non-Hispanic Black	40.8 (33.6, 48.4)	51.9 (44.5, 59.2)	0.88 (0.63, 1.25)	0.94 (0.58, 1.52)	7.3 (4.6, 11.5)	0.63 (0.35, 1.14)	0.88 (0.41, 1.91)
Hispanic	51.9 (43.8, 59.9)	40.4 (33.3, 48.0)	0.54** (0.37, 0.79)	0.63 (0.39, 1.03)	7.7 (4.5, 12.7)	0.52* (0.27, 1.00)	0.78 (0.37, 1.64)
Non-Hispanic Asian	49.7 (38.3, 61.2)	36.8 (27.6, 47.1)	0.52** (0.33, 0.82)	0.43*** (0.26, 0.70)	13.4 (7.5, 23.0)	0.95 (0.45, 2.04)	0.56 (0.25, 1.25)
Non-Hispanic Other	41.1 (28.2, 55.4)	53.0 (39.3, 66.3)	0.90 (0.48, 1.68)	0.98 (0.48, 2.00)	5.9 (3.3, 10.4)	0.50 (0.24, 1.07)	0.47 (0.16, 1.37)
Age							
18–34	42.9 (36.2, 49.9)	46.2 (40.1, 52.4)	Ref	Ref	10.9 (7.5, 15.6)	Ref	Ref
35–49	37.2 (31.6, 43.2)	51.9 (45.8, 58.1)	1.30 (0.86, 1.96)	1.27 (0.82, 1.97)	10.8 (7.5, 15.3)	1.14 (0.63, 2.07)	1.11 (0.59, 2.08)
50-64	39.7 (35.6, 44.0)	52.9 (48.7, 57.0)	1.24 (0.90, 1.69)	1.32 (0.93, 1.89)	7.4 (5.9, 9.3)	0.73 (0.42, 1.29)	0.90 (0.51, 1.59)
65–74	35.7 (30.7, 41.0)	56.2 (50.7, 61.6)	1.46 (0.99, 2.16)	1.99** (1.30, 3.04)	8.1 (6.0, 10.9)	0.89 (0.49, 1.64)	1.64 (0.84, 3.22)
75+	56.1 (49.4, 62.6)	37.2 (31.6, 43.1)	0.62* (0.43, 0.89)	0.84 (0.44, 1.57)	6.7 (4.3, 10.2)	0.47* (0.25, 0.89)	0.82 (0.28, 2.39)
Education							
Less than HS	68.2 (58.2, 76.7)	29.7 (21.3, 39.6)	Ref	Ref	2.2 (1.2, 3.9)	Ref	Ref
HS Grad	53.6 (48.0, 59.1)	44.1 (38.7, 49.7)	1.89* (1.16, 3.08)	1.79 (0.84, 3.85)	2.3 (1.4, 3.8)	1.35 (0.63, 2.88)	0.99 (0.35, 2.80)
Some College	41.9 (37.6, 46.3)	51.7 (47.1, 56.2)	2.84*** (1.78, 4.51)	2.09 (0.97, 4.48)	6.5 (4.3, 9.7)	4.88*** (2.26, 10.52)	2.45 (0.85, 7.02)

	Prevalence <sup><i>a</i></sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Don't know anything	Know a little	Know a little compared to Don't know	Know a little compared to Don't know	Know a lot	Know a lot compared to Don't know	Know a lot compared to Don't know
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Bachelor's Degree or Higher	23.9 (20.1, 28.1)	56.0 (51.9, 59.9)	5.39*** (3.22, 9.01)	4.09** (1.79, 9.37)	20.2 (16.7, 24.2)	26.68*** (13.00, 54.76)	16.10*** (5.84, 44.40)
Income							
< \$20,000	49.8 (42.4, 57.1)	41.4 34.4, 48.8)	Ref	Ref	8.8 (5.6, 13.5)	Ref	Ref
\$20,000-35,000	43.3 (35.7, 51.2)	50.6 (42.8, 58.3)	1.40 (0.88, 2.23)	1.35 (0.68, 2.67)	6.1 (3.2, 11.5)	0.80 (0.37, 1.76)	0.66 (0.25, 1.80)
\$35,000-50,000	50.1 (42.5, 57.7)	41.8 (34.9, 49.0)	1.00 (0.63, 1.61)	0.80 (0.42, 1.52)	8.1 (5.1, 12.8)	0.92 (0.43, 1.96)	0.52 (0.20, 1.29)
\$50,000-75,000	38.8 (33.2, 44.7)	54.5 (49.0, 59.9)	1.69* (1.12, 2.55)	1.36 (0.79, 2.34)	6.7 (4.3, 10.3)	0.98 (0.48, 2.00)	0.58 (0.24, 1.37)
\$75,000+	35.6 (31.5, 40.0)	52.1 (48.0, 56.2)	1.76** (1.25, 2.47)	1.02 (0.61, 1.73)	12.3 (9.6, 15.6)	1.95* (1.05, 3.63)	0.62 (0.29, 1.32)
Urban-Rural							
Small town/rural	40.7 (30.5, 51.8)	53.1 (42.2, 63.7)	Ref	Ref	6.2 (2.4, 14.9)	Ref	Ref
Micropolitan	51.3 (40.3, 62.1)	40.0 (30.0, 50.9)	0.60 (0.32, 1.12)	0.47 (0.20, 1.09)	8.8 (4.3, 17.1)	1.13 (0.31, 4.13)	0.96 (0.23, 4.0)
Metropolitan	40.4 (37.5, 43.5)	49.9 (47.2, 52.6)	0.95 (0.58, 1.55)	0.67 (0.34, 1.33)	9.6 (8.0, 11.5)	1.57 (0.57, 4.36)	1.35 (0.39, 4.64)
Cancer History							
No	41.6 (38.8, 44.5)	49.1 (46.5, 51.8)	Ref	Ref	9.2 (7.6, 11.1)	Ref	Ref
Yes	36.2 (30.1, 42.7)	54.4 (48.3, 60.3)	1.27 (0.94, 1.72)	1.34 (0.84, 2.13)	9.5 (7.2, 12.4)	1.18 (0.77, 1.81)	1.31 (0.74, 2.29)
Discuss with Healt	hcare Providers						
Emailed to communicate with healthcare providers							
No	51.7 (48.0, 55.4)	43.1 (39.4, 46.9)	Ref	Ref	5.2 (4.2, 6.4)	Ref	Ref
Yes	29.1 (25.4, 33.2)	56.9 (53.0, 60.8)	2.34*** (1.81, 3.04)	1.66** (1.18, 2.34)	14.0 (11.4, 17.0)	4.77*** (3.49, 6.52)	2.47*** (1.55, 3.92)
Used a tablet or smartphone to help with discussions with health care provider							
No	44.6 (40.8, 48.4)	47.5 (43.8, 51.2)	Ref	Ref	7.9 (6.1, 10.2)	Ref	Ref
Yes	30.1 (25.7, 34.8)	56.3 (51.5, 61.0)	1.76*** (1.32, 2.34)	1.19 (0.81, 1.75)	13.6 (10.8, 17.1)	2.55*** (1.68, 3.87)	1.06 (0.58, 1.92)

	Prevalence <sup><i>a</i></sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Don't know anything		Know a little compared to Don't know	Know a little compared to Don't know	Know a lot	Know a lot compared to Don't know	Know a lot compared to Don't know
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Seek Health Information							
Use Internet to look for health- related information							
No	57.2 (52.2, 62.0)	39.2 (34.5, 44.2)	Ref	Ref	3.6 (2.6, 4.9)	Ref	Ref
Yes	35.3 (32.2, 38.5)	53.2 (50.2, 56.2)	2.20*** (1.71, 2.83)	1.16 (0.81, 1.67)	11.5 (9.6, 13.8)	5.19*** (3.43, 7.85)	1.60 (0.89, 2.89)
Used tablet or smartphone to make decisions about health							
No	40.0 (35.9, 44.3)	51.3 (47.4, 55.1)	Ref	Ref	8.7 (6.8, 11.0)	Ref	Ref
Yes	37.2 (32.4, 42.1)	50.6 (46.2, 55.0)	1.06 (0.80, 1.42)	0.69 (0.47, 1.01)	12.2 (9.6, 15.5)	1.52 (0.98, 2.35)	0.89 (0.54, 1.47)
Visited a social networking site e.g., Facebook							
No	52.1 (47.3, 56.9)	41.5 (37.1, 46.1)	Ref	Ref	6.4 (4.4, 9.0)	Ref	Ref
Yes	37.3 (34.0, 40.8)	52.3 (49.3, 55.3)	1.76*** (1.37, 2.26)	1.28 (0.83, 1.95)	10.3 (8.3, 12.7)	2.27** (1.35, 3.80)	1.17 (0.59, 2.34)
Watch health- related videos on Youtube							
No	46.6 (43.1, 50.1)	47.1 (43.7, 50.6)	Ref	Ref	6.3 (5.1, 7.7)	Ref	Ref
Yes	32.6 (28.5, 37.1)	53.6 (48.9, 58.2)	1.62*** (1.24, 2.12)	1.24 (0.85, 1.81)	13.8 (11.0, 17.1)	3.15*** (2.27, 4.37)	1.90** (1.22, 2.97)
Share Information							
Use social network to share health-related info							
No	43.3 (40.3, 46.3)	48.0 (45.2, 50.9)	Ref	Ref	8.7 (7.2, 11.1)	Ref	Ref
Yes	26.6 (21.3, 32.7)	60.0 (53.1, 66.4)	2.03*** (1.44, 2.87)	1.40 (0.92, 2.14)	13.4 (9.7, 18.4)	2.53*** (1.68, 3.80)	1.19 (0.70, 2.01)
Use health- related online forum or support group							
No	43.5 (40.7, 46.4)	47.9 (45.2, 50.6)	Ref	Ref	8.6 (7.3, 10.0)	Ref	Ref

	Prevalence <sup>a</sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Don't know anything	Know a little	Know a little compared to Don't know	Know a little compared to Don't know	Know a lot	Know a lot compared to Don't know	Know a lot compared to Don't know
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Yes	17.8 (12.6 24.4)	65.5 (56.8, 73.4)	3.35*** (2.16, 5.21)	2.21*** (1.41, 3.46)	16.7 (10.5, 25.5)	4.78*** (2.59, 8.83)	2.56** (1.31, 5.00)

<sup>a</sup> prevalence estimates of percentages (with 95% confidence intervals) generated by cross-classification of response option levels of each correlate by levels of clinical trial knowledge

*b* odds ratios (unadjusted) from logistic regression models testing differences in correlate response options by level of clinical trial knowledge (for this column, comparing "Know a little" to "Don't know anything" (reference))

 $^{c}$  adjusted odds ratio estimates from a single logistic regression model testing differences in correlate response options by levels of clinical trial knowledge (for this column, comparing "Know a little" to "Don't know anything" (reference))

d odds ratios (unadjusted) from logistic regression models testing differences in correlate response options by levels of clinical trial knowledge (for this column, comparing "Know a lot" to "Don't know anything" (reference))

 $e^{a}$  adjusted odds ratio estimates from a single logistic regression model testing differences in correlate response options by levels of clinical trial knowledge (for this column, comparing "Know a lot" to "Don't know anything" (reference))

#### Table 4

Prevalence and correlates of most trusted source for clinical trials-related health information by demographics, health status, and health communication behaviors

	Prevalence <sup>a</sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Providers	Health Orgs <sup>f</sup>	Health Orgs Compared to Providers	Health Orgs Compared to Providers	Social Support <sup>g</sup>	Social Support Compared to Providers	Social Support Compared to Providers
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Entire Sample	73.6 (71.0, 76.0)	19.4 (17.2, 21.7)			7.1 (5.8, 8.6)		
Demographics							
Gender							
Male	73.0 (68.8, 76.8)	19.8 (16.5, 23.6)	Ref	Ref	7.2 (5.1, 10.0)	Ref	Ref
Female	75.0 (72.0, 77.8)	17.9 (15.5, 20.7)	0.88 (0.67, 1.15)	1.18 (0.86, 1.63)	7.1 (5.5, 9.1)	0.96 (0.61, 1.52)	0.91 (0.56, 1.48)
Race/Ethnicity							
Non-Hispanic White	74.8 (71.5, 77.8)	18.1 (15.5, 21.0)	Ref	Ref	7.1 (5.4, 9.4)	Ref	Ref
Non-Hispanic Black	76.0 (69.7, 81.3)	18.0 (13.4, 23.7)	0.98 (0.68, 1.43)	1.13 (0.72, 1.77)	6.0 (3.6, 10.0)	0.83 (0.45, 1.54)	1.31 (0.61, 2.79)
Hispanic	66.9 (59.9, 73.3)	25.6 (19.7, 32.5)	1.58 <sup>*</sup> (1.07, 2.35)	1.76 <sup>*</sup> (1.06, 2.92)	7.5 (4.6, 11.8)	1.17 (0.66, 2.07)	1.03 (0.49, 2.16)
Non-Hispanic Asian	71.7 (57.9, 81.5)	22.7 (13.6, 35.6)	1.32 (0.68, 2.59)	1.43 (0.68, 3.01)	6.1 (2.3, 15.5)	0.91 (0.29, 2.83)	1.04 (0.32, 3.43)
Non-Hispanic Other	64.8 (47.9, 78.7)	23.5 (12.5, 39.8)	1.50 (0.68, 3.32)	0.84 (0.34, 2.08)	11.7 (4.9, 25.5)	1.89 (0.67, 5.31)	0.72 (0.17, 3.05)
Age							
18–34	68.9 (61.6, 75.3)	24.4 (19.1, 30.7)	Ref	Ref	6.7 (3.8, 11.5)	Ref	Ref
35–49	69.9 (64.2, 75.0)	22.1 (17.7, 27.1)	0.89 (0.58, 1.38)	0.88 (0.57, 1.37)	8.1 (5.4, 11.9)	1.18 (0.54, 2.61)	0.98 (0.44, 2.22)
50–64	76.3 (72.3, 79.9)	15.7 (12.7, 19.3)	0.58 <sup>**</sup> (0.39, 0.86)	0.64 (0.40, 1.02)	8.0 (6.0, 10.5)	1.08 (0.54, 2.17)	0.82 (0.40, 1.66)
65–74	78.8 (74.3, 82.8)	16.0 (13.0, 19.5)	0.57 <sup>**</sup> (0.39, 0.85)	0.69 (0.41, 1.15)	5.2 (3.1, 8.4)	0.68 (0.29, 1.58)	1.07 (0.44, 2.64)
75+	80.3 (73.3, 85.6)	14.4 (9.4, 21.4)	0.51 <sup>*</sup> (0.27, 0.94)	1.29 (0.51, 3.29)	5.3 (3.5, 7.9)	0.68 (0.31, 1.50)	1.83 (0.73, 4.60)
Education							
Less than HS	84.0 (74.4, 90.5)	11.8 (6.2, 21.4)	Ref	Ref	4.2 (1.7, 9.7)	Ref	Ref
HS Grad	84.9 (79.7, 89.0)	9.0 (6.0, 13.2)	0.75 (0.32, 1.78)	0.90 (0.28, 2.86)	6.2 (3.6, 10.3)	1.47 (0.50, 4.29)	0.86 (0.23, 3.32)
Some College	68.3 (63.5, 72.8)	22.5 (18.4, 27.2)	2.34 <sup>*</sup> (1.08, 5.07)	3.38 <sup>*</sup> (1.18, 9.66)	9.2 (6.6, 12.6)	2.71 <sup>*</sup> (1.05, 7.04)	1.69 (0.53, 5.45)

	Prevalence <sup><i>a</i></sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Providers	Health Orgs <sup>f</sup>	Health Orgs Compared to Providers	Health Orgs Compared to Providers	Social Support <sup>g</sup>	Social Support Compared to Providers	Social Support Compared to Providers
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Bachelor's Degree or Higher	69.5 (65.2, 73.4)	25.0 (21.4, 29.0)	2.56 <sup>*</sup> (1.20, 5.49)	3.84 <sup>*</sup> (1.32, 11.14)	5.5 (4.3, 7.0)	1.61 (0.61, 4.26)	0.80 (0.21, 3.02)
Income							
< \$20,000	75.1 (68.0, 81.1)	21.6 (15.8, 28.7)	Ref	Ref	3.3 (2.0, 5.5)	Ref	Ref
\$20,000-35,000	74.9 (68.4, 80.4)	18.6 (13.3, 25.2)	0.86 (0.50, 1.49)	0.55 (0.28, 1.08)	6.5 (3.7, 11.4)	1.98 (0.87, 4.51)	2.27 (0.79, 6.53)
\$35,000-50,000	75.9 (68.1, 82.3)	17.7 (11.9, 25.6)	0.82 (0.45, 1.47)	0.58 (0.28, 1.19)	6.3 (3.7, 10.7)	1.90 (0.87, 4.15)	3.36 <sup>*</sup> (1.18, 9.55)
\$50,000-75,000	76.3 (69.7, 81.9)	18.8 (14.0, 24.8)	0.86 (0.51, 1.45)	0.48 <sup>*</sup> (0.26, 0.89)	4.8 (3.1, 7.5)	1.43 (0.69, 2.96)	1.43 (0.54, 3.83)
\$75,000+	70.0 (65.6, 74.1)	20.1 (16.6, 24.1)	1.00 (0.63, 1.58)	0.44 <sup>**</sup> (0.23, 0.77)	9.9 (7.3, 13.4)	3.23 *** (1.70, 6.11)	4.19 <sup>**</sup> (1.63, 10.76)
Urban-Rural				,			,
Small town/rural	75.3 (62.1, 85.1)	20.9 (11.4, 35.3)	Ref	Ref	7.2 (5.8, 9.0)	Ref	Ref
Micropolitan	83.1 (76.8, 88.0)	9.8 (6.4, 14.7)	0.42 <sup>*</sup> (0.19, 0.94)	0.37 <sup>*</sup> (0.15, 0.95)	7.1 (4.2, 11.7)	1.74 (0.69, 4.38)	2.27 (0.50, 10.29)
Metropolitan	72.6 (69.6, 75.4)	20.2 (17.7, 22.9)	1.00 (0.46, 2.16)	0.71 (0.30, 1.69)	3.7 (1.7, 8.1)	2.02 (0.87, 4.72)	2.30 (0.60, 8.73)
Cancer History							
No	72.6 (69.7, 75.2)	20.0 (17.7, 22.6)	Ref	Ref	7.4 (6.0, 9.1)	Ref	Ref
Yes	80.5 (75.4, 84.8)	15.3 (11.2, 20.6)	0.69 (0.47, 1.01)	0.84 (0.49, 1.44)	4.2 (2.7, 6.4)	0.51 <sup>**</sup> (0.32, 0.83)	0.81 (0.46, 1.42)
Discuss with Healt	thcare Providers						
Emailed to communicate with healthcare providers							
No	74.6 (70.9, 78.0)	17.0 (14.2, 20.3)	Ref	Ref	8.4 (6.2, 11.4)	Ref	Ref
Yes	72.1 (68.3, 75.6)	22.2 (19.1, 25.8)	1.36 <sup>*</sup> (1.02, 1.81)	1.06 (0.75, 1.50)	5.7 (4.4, 7.3)	0.70 (0.44, 1.11)	0.60 (0.35, 1.03)
Used a tablet or smartphone to help with discussions with health care provider							
No	71.1 (67.2, 74.6)	20.0 (16.8, 23.5)	Ref	Ref	9.0 (6.8, 11.7)	Ref	Ref
Yes	74.9 (70.8, 78.6)	20.4 (16.8, 23.50	0.97 (0.72, 1.31)	0.71 (0.50, 1.01)	4.7 (3.3, 6.4)	0.49 <sup>**</sup> (0.31, 0.79)	0.53 (0.28, 1.00)

	Prevalence <sup><i>a</i></sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Providers	Providers Health Orgs <sup>f</sup>	Health Orgs Compared to Providers Unadjusted OR (95% CI)	Health Orgs Compared to Providers	Social Support <sup>g</sup>	Social Support Compared to Providers	Social Support Compared to Providers
	% (95% CI)	% (95% CI)		Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Seek Health Information							
Use Internet to look for health- related information							
No	82.9 (78.4, 86.6)	12.1 (8.9, 16.3)	Ref	Ref	4.9 (3.4, 7.1)	Ref	Ref
Yes	70.0 (66.9, 72.8)	22.1 (19.5, 25.0)	2.16 <sup>***</sup> (1.47, 3.18)	1.67 <sup>*</sup> (1.00, 2.77)	7.9 (6.3, 9.9)	1.90 <sup>**</sup> (1.18, 3.06)	1.77 (0.80, 3.93)
Used tablet or smartphone to make decisions about health							
No	73.6 (69.8, 77.1)	19.1 (16.0, 22.6)	Ref	Ref	7.3 (5.6, 9.5)	Ref	Ref
Yes	71.2 (66.8, 75.2)	21.6 (17.9, 25.8)	1.17 (0.85, 1.61)	0.86 (0.63, 1.18)	7.2 (4.9, 10.5)	1.02 (0.61, 1.72)	0.93 (0.46, 1.90)
Visited a social networking site e.g., Facebook							
No	78.7 (74.1, 82.6)	16.3 (12.7, 20.7)	Ref	Ref	5.0 (3.6, 7.1)	Ref	Ref
Yes	71.7 (68.4, 74.8)	20.9 (18.1, 23.9)	1.41 (0.99, 2.00)	1.19 (0.73, 1.94)	7.4 (5.8, 9.4)	1.61 <sup>*</sup> (1.01, 2.56)	1.28 (0.67, 2.45)
Watch health- related videos on Youtube							
No	78.7 (75.5, 81.5)	15.9 (13.3, 19.0)	Ref	Ref	5.4 (4.1, 7.0)	Ref	Ref
Yes	65.8 (60.8, 70.5)	25.1 (21.1, 29.6)	1.88 *** (1.34, 2.63)	1.51 <sup>*</sup> (1.03, 2.21)	9.1 (6.6, 12.3)	2.01 <sup>**</sup> (1.27, 3.18)	2.28 <sup>**</sup> (1.29 4.02)
Share Information							
Use social network to share health-related info							
No	73.6 (70.7, 76.3)	19.6 (17.0, 22.4)	Ref	Ref	6.8 (5.4, 8.5)	Ref	Ref
Yes	72.4 (65.2, 78.5)	20.7 (15.0, 27.8)	1.08 (0.68, 1.69)	0.85 (0.51, 1.41)	7.0 (4.5, 10.6)	1.04 (0.62, 1.75)	0.91 (0.50, 1.64)
Use health- related online forum or support group							
No	74.6 (71.8, 77.1)	18.9 (16.7, 21.3)	Ref	Ref	6.5 (5.2, 8.2)	Ref	Ref

	Prevalence <sup><i>a</i></sup>	Prevalence	OR <sup>b</sup>	AOR <sup>c</sup>	Prevalence	OR <sup>d</sup>	AOR <sup>e</sup>
Correlates	Providers	Health Orgs <sup>f</sup>	Health Orgs Compared to Providers	Health Orgs Compared to Providers	Social Support <sup>g</sup>	Social Support Compared to Providers	Social Support Compared to Providers
	% (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	% (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Yes	63.1 (53.8, 71.6)	27.4 (19.1, 37.7)	1.71 <sup>*</sup> (1.05, 2.80)	1.19 (0.69, 2.06)	9.4 (5.8, 15.0)	1.70 (0.94, 3.08)	1.45 (0.72, 2.92)

<sup>a</sup> prevalence estimates of percentages (with 95% confidence intervals) generated by cross-classifications of correlate response options by most trusted information source

<sup>b</sup> odds ratios (unadjusted) from logistic regression models testing differences in correlate response options by levels of most trusted information source (for this column, comparing Health Organizations to Providers (reference))

 $^{C}$  adjusted odds ratio estimates from a single logistic regression model testing differences in correlate response options by most trusted information source (for this column, comparing Health Organizations to Providers (reference))

<sup>d</sup> odds ratios (unadjusted) from logistic regression models testing differences in correlate response options by levels of most trusted information source (for this column, comparing Social Support to Providers (reference))

 $e^{a}$  adjusted odds ratio estimates from a single logistic regression model testing differences in correlate response options by most trusted information source (for this column, comparing Social Support to Providers (reference))

f combined response options "government health agencies" and "health organizations"

g combined response options "my family and friends" and "disease support groups"

Note. CI, confidence interval; OR, odds ratio; AOR, odds ratio; Ref, reference category.

\*\*\* = p<.001;

\*\* = p<.01;

\* = p<.05