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Novel method for recruiting representative at-risk individuals into cancer prevention trials: on-line health risk assessment in employee wellness programs

Siu-kuen Azor Hui, Ph.D., MSPH¹, Suzanne M. Miller, Ph.D.¹, Leah Hazuda, M.S.¹, Kimberly Engelman, Ph.D.², and Edward F. Ellerbeck, M.D., MPH²

¹Cancer Prevention and Control Program, Fox Chase Cancer Center / Temple University Health System, 333 Cottman Ave., Philadelphia, PA 19111

²Department of Preventive Medicine and Public Health, University of Kansas Medical Center, 3901 Rainbow Blvd., MS 1008, Kansas City, KS 66160

Abstract

Participation in cancer prevention trials (CPT) is lower than 3% among high-risk healthy individuals, and racial/ethnic minorities are the most under-represented. Novel recruitment strategies are therefore needed. On-line health risk assessment (HRA) serves as a gateway component of nearly all employee wellness programs (EWP) and may be a missed opportunity. This study aimed to explore employees' interest, willingness, motivators, and barriers of releasing their HRA responses to an external secure research database for recruitment purpose. We used qualitative research methods (focus group and individual interviews) to examine employees' interest and willingness in releasing their on-line HRA responses to an external, secure database to register as *potential* CPT participants. Fifteen structured interviews (40% of study participants were of racial/ethnic minority) were conducted and responses reached saturation after four interviews. All employees showed interest and willingness to release their on-line HRA responses to register as a *potential* CPT participant. Content analyses revealed that 91% of participants were motivated to do so, and the major motivators were to: 1) obtain help in finding personally relevant prevention trials, 2) help people they know who are affected by cancer, and/or 3) increase knowledge about CPT. A subset of participants (45%) expressed barriers of releasing their HRA responses due to concerns about credibility and security of the external database. On-line HRA may be a feasible but underutilized recruitment method for cancer prevention trials. EWP-sponsored HRA shows promise for the development of a large, centralized registry of racially/ethnically representative CPT potential participants.

Address correspondence to: Siu-kuen Azor Hui, Ph.D., M.S.P.H., Cancer Prevention and Control Program, Fox Chase Cancer Center / Temple University Health System, 333 Cottman Avenue, P4171, Philadelphia, PA 19111; SKAzor.Hui@fccc.edu; telephone: (215) 728-2453; fax: (215) 214-2178.

Conflict of Interest Statement

All authors declare that there is no conflict of interest.

Keywords

Cancer Prevention Trials; Cancer Clinical Trials; Clinical Trials Recruitment; Recruitment Strategy; Employee Wellness Program; On-line Health Risk Assessment; Health Communication; Electronic Health Data Transfer; Cancer Risk Registry

Clinical cancer prevention trials (CPT) are the type of cancer clinical trial that evaluate new interventions to lower the risk of developing certain types of cancer. Most of these trials involve healthy individuals who have a higher than average risk of developing cancer but are not yet diagnosed. Some CPT include individuals who have had cancer before, and these trials aim to prevent recurrence of the original cancer or prevent development of a new type of cancer [1]. If the US is to advance in translational science in cancer prevention and control, it is critical to recruit sufficient and racially/ethnically representative individuals from the larger general population to participate in CPT. Unfortunately, participation rates in cancer clinical trials are low. Recent studies showed that fewer than 3% of adult cancer patients participate in cancer clinical treatment trials [2, 3], and the participation rate in CPT is likely to be even lower [4], as healthy individuals do not tend to consider clinical trials. Additionally, individuals of racial/ethnic minorities are under-represented, compared to the general US population, among trial participants. The enrollment of racially and ethnically representative participants into cancer clinical trials is critical to the generalizability of findings from such trials [5]. Yet, studies on racial/ethnic disparity in participation in cancer clinical trials have found that Hispanics and African-Americans are significantly less likely to participate in cancer research, even though the minorities bear a disproportionate burden of cancer morbidity and mortality [2, 3, 6-13]. Since at least one-third of cancers can be prevented [13, 14], and the economic burden of cancer is high [13], this study focused on developing a novel recruitment strategy for enrolling racially and ethnically representative at-risk individuals into CPT.

Potential clinical trial participants face awareness barriers, opportunity barriers, and decision-making barriers [15-17]. Racial/ethnic minorities experience additional distinct barriers unique to their cultures [12, 16]. For instance, Latinos often report lack of information about health and research and language difficulties as barriers; whereas African-Americans report barriers related to racism and distrust of healthcare systems and medical research [8, 9, 12, 18-21]. For barriers to CPT recruitment specifically, lack of access to an eligible population for CPT was the most cited barrier among oncologists, and lack of knowledge and other psychosocial barriers were commonly endorsed among higher cancer risk individuals [4]. A novel recruitment strategy is needed to overcome these major barriers of CPT recruitment.

The large and diverse US employee population and increasingly popular employee wellness programs (EWP) are untapped resources with a significant potential to improve recruitment into CPT. EWP are defined as organized, employer-sponsored programs that strive to promote a healthy lifestyle for employees, maintain or improve health and well-being, and prevent or delay the disease onset [22]. At their core, these programs offer assessment of participants' health risks (health risk assessment or HRA) and deliver tailored educational and lifestyle management interventions designed to lower the identified risk factors and

improve health outcomes [22]. In 2013, about 144 million adults, including an estimated 16 million African-Americans and 22 million Hispanics, were employed [23, 24]. In addition, a recent report indicated that 92% of employers with at least 200 employees offer EWP [25]. Nearly all EWP use HRA with personalized feedback as the gateway to other EWP components. The HRA is a self-report questionnaire that assesses an employee's risk for developing common chronic diseases, including cancer. A standard HRA assesses several cancer risk factors, including biological (e.g. age, race, personal history) and lifestyle (e.g. smoking, diet, exercise, alcohol use) ones, as well as cancer screening behaviors (e.g. mammography, Pap test, colonoscopy) [26]. Following completion of the HRA, an employee receives personalized disease risk feedback and recommendations for preventive health care. The personal HRA responses provide valuable clinical information that could be used to identify higher cancer risk employees and link them to CPT. Moreover, presenting the opportunity to participate in CPT on HRA is consistent with the prevention philosophy of EWP, which is to encourage at-risk employees to engage in proactive health behaviors to prevent chronic disease.

As HRAs are increasingly administered on-line, they offer more opportunities for tailored and state-of-the-science digital health communications to address the major CPT recruitment barriers mentioned above, and allow more efficient health data transfer. For instance, basic educational information about CPT could be presented near the cancer-related questions on the HRA and/or provided on the personalized HRA risk feedback webpage, to address awareness and knowledge barriers. Opportunities for participating in currently available CPTs and a hyper-link to register as a *potential* CPT participant by releasing one's HRA responses could also be presented as part of the personalized preventive care recommendations on the risk feedback webpage (See Figure 1). These strategies would address opportunity and decision-making barriers, because details about specific CPT and decisions are not needed at the time of taking the HRA and releasing the responses. Indeed, participants simply would need to agree to share their HRA responses with a CPT specialist. The centralized CPT specialist would then make an initial decision regarding trial eligibility and make additional, proactive contact with individual employees when appropriate trials were available. Further personalized discussion and decision counseling on particular trial opportunities could also occur with the CPT specialist at this time. Figure 2 shows the proposed HRA data flow and potential recruitment protocol. With this protocol, employees would be less likely to be overwhelmed with sifting through the myriad of CPT and eligibility criteria.

Another advantage of using the HRA as a recruitment method is that employees taking the HRA are at a moment of heightened motivation to improve their health status. Thus, recruiting HRA participants into CPT may be more effective than in other community settings. Further, on-line HRA can be tailored easily to appropriate languages and cultural attitudes to address language and cultural barriers. To alleviate the issue of employee distrust, HRA are always assured to be confidential by the HRA vendors so that employers cannot access these individual-level health data.

In summary, HRA in EWP is a promising opportunity to recruit racial/ethnically representative at-risk individuals into CPTs. However, little is known about the feasibility of

leveraging it for CPT accrual. The objectives of the current study were to investigate the feasibility of this new recruitment strategy through an exploration of the interest, willingness, motivators, and barriers of employees as they relate to utilizing on-line HRA for learning about and registering as potential participants of CPT.

METHODS

We carried out a qualitative study using focus group and semi-structured individual interviews methodology to examine employees' knowledge and perception of CPTs, as well as to explore their interest and willingness to use the on-line HRA in the EWP to register as *potential* participants in CPTs. We collaborated with a local, large health system employer, Temple University Health System (TUHS), to recruit employees who were eligible for their EWP (Be Your Best). The "Be Your Best" program began in Fall 2011 for TUHS employees and their spouses/partners who are enrolled in TUHS health plans. All eligible TUHS employees could earn reward points by participating in the annual on-line HRA, biometric screening, and completing health goals. When a set number of points are achieved, the employee and his/her spouse receive a 10% discount on their health insurance premiums the next year. At the time of this study, Independence Blue Cross provided 90% of TUHS health plans and all wellness program services, including the on-line HRA. The employee population of TUHS in 2012 was 5,520 and about 32% of them were of African-American race and 9% of them were of Hispanic/Latino ethnicity. This study was approved by the Institutional Review Board of Fox Chase Cancer Center (FCCC).

Participants

Employees were recruited through "Be Your Best" communications materials (e.g., emails, print newsletters,) and activities (wellness seminars and health fairs), as well as study flyers posted at all TUHS worksites. Recruitment lasted from June 2013 – December 2013. Interested employees who contacted study staff were screened for eligibility over the telephone. Participants were eligible if they were over the age of 17, enrolled in a TUHS health plan, had completed an HRA and onsite biometric screening in the past two years, had no serious medical conditions, and could read, write, and communicate with ease in English. Eligible employees' work schedules were obtained for potential participation in either a focus group or individual interview. The focus group and interviews were scheduled at one of the five TUHS hospital or corporate office worksites where the participant worked. Over the recruitment period, 49 employees were screened and 42 of them were eligible. Of these, 36 (85.7%) were women, 25 (59.5%) were Caucasians, 14 (33.3%) were African-American, and 4 (9.5%) were Hispanic/Latino. We attempted to organize focus groups that consist of employees who are of the same racial/ethnic background in each group to explore any race/ethnic-specific responses; however, due to logistical difficulties, only one focus group of Caucasian employees at the largest hospital worksite was held. The final study sample was 15, including 5 from the focus group and 10 individual interview participants who are of various racial and ethnic backgrounds. Detailed demographic characteristics of the study participants are reported in Table 1.

Measures

Demographic questionnaire—Demographic characteristics including age, race/ethnicity, level of education, income, and employment status were collected by a simple self-administered questionnaire.

Focus group moderation/individual interview guide—A focus group/individual interview guide was developed to examine employees' interest and willingness to release their on-line HRA data for CPT recruitment. The interview guide questions focused on the feasibility of a proposed on-line HRA data flow recruitment strategy. It included open-ended questions about perceptions and knowledge of cancer risk and CPT, interest in participating in CPT, and willingness to sign up for *potential* CPTs through releasing their on-line HRA responses. Some example questions on the guide are:

- “What do you know about cancer prevention trials?”
- “What do you think about presenting educational information on cancer prevention trials near the cancer-related questions on the on-line HRA?”
- “How do you feel about agreeing to be a *potential* participant in cancer prevention trials?”
- “What are some reasons you are or are not willing to release your HRA responses to a secure research database?”
- “What are some motivating ways to tell you about participating in cancer prevention trials?”

In addition to the guide, the moderator also used a sketch diagram of the proposed data flow (see Figure 2) for illustration and explaining of the proposed recruitment strategy to the participants.

Procedure

After study participants were scheduled for a focus group or individual interview, the group/interview was conducted at the participant's worksite in a private space with a computer equipped with internet access. The computer with internet access was used to show the on-line HRA on Independent Blue Cross wellness program website and the potential locations of the new CPT educational and/or recruitment messages on the webpages. All individual interviews and focus group discussion were led by the principal investigator of this project. The focus group was audio- and video-recorded to capture any salient non-verbal individual or group communications, while all individual interviews were audio-recorded. A moderator assistant was also present to observe and take notes of important participant responses and reactions to ensure no information was missed. Throughout the interview process, participants were encouraged to express their personal thoughts and feelings in response to the questions. Since all participants indicated that they had no knowledge about CPT, the interviewer also needed to provide basic educational information about them during the focus group and interviews (e.g. definition and types of CPT).

Upon completion of the focus group or interview, each participant was asked to complete a brief demographic questionnaire. Participants received a gift card as compensation. Focus group and interview recordings were then transcribed by study staff. Initially transcriptions were “open coded”: identifying within the text key words, themes, and descriptions of behavior, based on the classic Grounded Theory [27]. Subsequently, we grouped these themes into coding categories and develop a code map. The code map was entered into NVivo 10, a qualitative analysis software, for data organization. This allowed us to categorize and retrieve issues related to participants’ interest and willingness of using HRA as an opportunity to register for CPTs. Key ideas, words, and statements that expressed distinct ideas/thoughts responding to the interview questions were categorized and organized by their conceptual relations. The manual coding was conducted by a master’s-level project manager under the supervision of the principal investigator of this project. The project manager was trained in qualitative data analysis in her graduate education. The categorization and conceptual relations of the ideas were discussed and agreed upon between the project manager and principal investigator, resulting in the overarching themes and sub-themes of the qualitative responses.

RESULTS

The participants’ demographic characteristics (age, gender, race/ethnicity, education, and income) are presented in Table 1.

Regarding results from the content analyses of focus group/individual interviews responses, the overarching themes that emerged were categorized into: (1) interest; (2) willingness; (3) motivators; and (4) barriers of releasing their on-line HRA responses for cancer prevention research recruitment purposes. Table 1 displays more sample quotes from study participants pertaining to each of these themes.

Interest

Study participants were unaware of CPT. Some participants associated them with clinical trials, but were unable to articulate the differences between clinical treatment and clinical prevention trials. Selected quotes from participants about knowledge in CPT are “I don’t know.”, “Nope, I know nothing about it.”, “Are they clinical trials? I sometimes see flyers in the elevator to recruit patients for clinical trials, are they similar things?”

When participants were asked about their interest in having basic educational information about cancer prevention trials added around the cancer-related questions on the HRA, all the participants showed considerable interest.

“I think that’s a great idea. Because you’ve got people at a point where they’re thinking about cancer, and if you put the information readily available to them that they could see it.”

Participants were asked whether they would be interested in having an electronic link at the end of their HRA and/or HRA feedback to release their data as a way to register for prevention trials, according to the proposed data flow and recruitment procedure presented in Figure 2. All of participants expressed interest in the opportunity to release their HRA

responses for CPT recruitment. Some were particularly interested in having someone review their cancer risk information to see if they were at high risk to determine whether they could benefit from a trial.

“I think that’s a good thing. Yeah, because this person gets to see if I’m a good fit for that kind of a study.” Others were interested in the knowledge they would gain from possibly being in contact with a CPT Specialist.

“...knowledge is power and the more knowledge I have of what is affecting me and what I can do to make things better for me is going to make things better for me as a person, as a whole, my life, my body.”

Willingness

All participants were willing to release their HRA responses for CPT recruitment. Knowing that there may be benefits from a prevention trial was associated with participants being more willing to release their HRA information. Participants indicated that the wording of the release statement would be an important factor in making one more willing to release.

“So I mean if you presented it as, you know, as there being benefits to it, I might be more apt to, but if you just ask, “Can I like give away your health information?” I probably wouldn’t do it.”

Knowing that a CPT Specialist would be reviewing their responses was also a factor that facilitated participants’ willingness to release their HRA responses.

“So reasons I would be willing to release is that it would help to, it would help the cancer prevention trial specialist to look at my information and then decide which trials would be best for me.”

Motivators

A large majority (91%) of participants had motivators to release their HRA responses. Informing family, friends, and patients about cancer risk and prevention methods were among the most common motivators.

“...to pass that information along to my family members and my friends and my patients.”

“...I just not think about myself, I have to think about my children.”

Participants also found it motivating to have a specialist review their information to possibly lower their risk of cancer.

“...I think people would see it as a positive thing if you put that and word it properly, that, you know, we have an expert in the field that’s going to walk you through this. You know, people just want a little assurance that, I think somebody cares and that they can respect them, you know for the results that they find and knowing that you’re going to help them I think is the big thing.”

Two participants mentioned wanting to learn more about their specific risk of cancer because of their racial/ethnic background.

“...I want to know whether I’ll have a higher chance for some cancers just because, you know, being an African-American...”

“...I’m really really interested in seeing the correlations between cancer and the backgrounds of my, not so much my gender but my ethnic background.”

Barriers

There was a concern among participants (45%) about the security of released HRA information. Many participants were worried about who would be reviewing or have access to their information. The threat of others “hacking” into the database of information was also mentioned. However, when reassured by the moderator that their information would be secure (i.e. security infrastructure of the system adheres to the most updated standard set by the National Institute of Health), all participants were agreeable with releasing their HRA data.

“My concern here is who is going to be this person that’s going to be reviewing my personal data?” “The reasons I would not like this so much is that I might have concerns about how secure is the secure database and is my personal health information um at risk, maybe of being hacked or is somebody else might get their hands on it and go to someplace that I might be unaware of.”

DISCUSSION

This qualitative study explored the feasibility of a new recruitment method for cancer prevention trials (CPT) through the on-line health risk assessment (HRA) questionnaire in the employee wellness programs (EWP). This prospective method takes advantage of the large, diverse employee population in the US, the increasingly popular on-line HRA that assesses cancer risk factors, and the possibility of electronic health data transfer system to build a centralized cancer risk registry. We studied employees’ interest, willingness, motivators, and barriers to releasing their HRA responses to a centralized, secure database, as a way to register for *potential* participation in CPT. Focus group and individual interviews findings indicate that employees are interested in and willing to take advantage of this proposed recruitment system. We found a large majority of participants (91%) expressed motivators to release their HRA data for cancer prevention research, while 45% of participants voiced some barriers of doing so.

Participant responses indicated that the proposed recruitment system of employees agreeing to release their on-line HRA responses in EWP could overcome knowledge barriers of CPT registration at several levels. First, the lack of basic knowledge about CPT could be addressed through presenting brief information around cancer-related questions on the on-line HRA, while the HRA participant’s attention is directed to his/her own cancer risk. Second, employees’ knowledge of their own cancer risk was not needed at the time of release. Study participants’ responses indicated that they would rather have a specialist review their personal cancer risk profiles and determine whether some CPT may be beneficial for them. Third, their knowledge of what is involved in trial participation and the potential benefit/risk balance were not needed at the time of release, because a specialist would reach out to the potential trial candidates to discuss details and personal benefit/risk

situation for decision support. All participants indicated interest in this pro-active approach of the specialist and the opportunity for personal, detailed discussion before deciding to participate in a CPT. With this new recruitment system, the initial knowledge requirement of CPT is minimal, only that is sufficient to be willing to release the HRA responses to an external, secure database for a specialist's review.

The main motivators to release on-line HRA responses for CPT recruitment were potential benefits to employees themselves or their family members (particularly children), in terms of knowing their cancer risk more precisely and ways to reduce the risk. The benefits were not limited to increased knowledge, but also the opportunity to actually engage in new ways of preventing the type of cancer for which the employee might be at higher personal risk. Several study participants also cited their close friends or colleagues who were affected by cancer as a motivator to help others who are at higher cancer risk. These perceived motivators of releasing HRA responses for CPT recruitment are important elements to be included when developing effective messages to be presented at the end of on-line HRA and/or its feedback. Similarly, the perceived barriers of releasing the on-line HRA responses are to be addressed in the motivating messages as well. A subset of the employees expressed concerns about personal health data security, credibility of the external, centralized database, and the credibility of the personnel who would have access to the database.

Electronic personal health data security during transfer and storage was the main perceived barrier to engage in this proposed CPT recruitment system. One potential avenue to address this barrier is the use of the "honest broker" system [28, 29], which began as an approach to integrate clinical care and research databases to promote clinical research participation. The "honest broker" system mediates between multiple clinical (e.g. primary care practices, specialty care clinic or hospitals, psychiatry care) and clinical research systems across institutions without compromising the protection of confidential personal health information. The system requires only one-time identity verification and manages data extraction and transfer, as well as electronic storage of personal health identifier for multiple clinical and research databases. This "honest broker" system for web-based, secure health data transfer was successful in a demonstration project in Michigan [29]. It facilitated clinical and translational research participation by significantly increasing the recruitment rate to 70% [29]. Our proposed new CPT recruitment method is innovative in that it extends the same electronic health data transfer system to health information (both behavioral and biometric data on the HRA) provided by employees in the worksite community for clinical prevention trials.

Limitations of the current study include a small study sample due to difficulties in recruitment, particularly the employees of racial/ethnic minority. Nonetheless, the proportion of participants from different racial/ethnic background in the final study sample was similar to the general US population. The responses from the focus group and individual interviews were convergent and we noticed the responses actually saturated after 4 interviews. Thus, despite the smaller than planned study sample, we likely captured all the important information. Another limitation of our study is that only employees who can read, write, and communicate with ease in English were eligible. This eligibility criterion was included because the on-line HRA currently provided by the TUHS EWP is available in English only.

Hispanic employees who lack basic English skills were excluded. This may have influenced the results in that the interest, willingness, motivators, and barriers of employees with lower level of English skills may have been different and not represented. However, the data we collected from the few bi-lingual Hispanic/Latino employees appeared to be similar to the non-Hispanic/Latino participants and were generally very positive. Spanish version of on-line HRA has emerged in the market and become more common, so future study can develop linguistically and culturally tailored motivating messages on the on-line HRA for CPT recruitment.

Low recruitment of research participants into CPT constitutes a major threat to the clinical and translational science enterprise of the National Cancer Institute of the US [30-33]. Our study proposes an innovative recruitment strategy for CPT through on-line HRA in EWP. We presented qualitative data that support this new strategy. This study is the first step for on-line HRA to be utilized as a standard method to create large cancer risk registries of racially/ethnically diverse potential CPT participants. Future implications of this research are better electronic health data integration, transfer, and security systems between community and clinical institutions for clinical prevention research, as advocated by the AHRQ [34], and integration of behavioral data into standard clinical data for research.

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Figure 1. Screen-shot of cancer risk feedback web page on a sample on-line HRA personalized risk feedback, and the proposed place to present new message about potential cancer prevention trial participation and the HRA responses release link

Figure 2.
Proposed new on-line HRA data flow and recruitment procedure

Table 1

Demographic characteristics of focus group and individual interview participants

	Total (N=15)
Age	Median: 57 years (range 26-63)
Gender	
Female	12 (80%)
Race	
White	9 (60%)
African-American	5 (33.3%)
Other	1 (6.7%)
Ethnicity	
Hispanic/Latino	2 (13.3%)
Education	
Some high school or less	0 (0%)
High school/GED	1 (6.67%)
Some college	3 (20%)
College graduate	6 (40%)
Post-graduate or professional degree	5 (33.33%)
Income	
\$20,000 or below	0 (0%)
\$20,001 – \$35,000	0 (0%)
\$35,001 – \$55,000	5 (33.33%)
\$55,001 – \$85,000	5 (33.33%)
\$85,001 – \$100,000	4 (26.67%)
\$100,001 or above	1 (6.67%)
Employment Status	
Full-time	15 (100%)

Table 2

Examples of quotes from participants indicating interests, willingness, motivators, and barriers of releasing their on-line health risk assessment (HRA) responses for cancer prevention trial recruitment purpose

	Sample quotes	Number and proportion of participants expressing these thoughts n (%)
Interest	"Yeah. There's no...having that available, there's absolutely no minus."	15 (100%)
	"I think that's a great idea. Because you've got people at a point where they're thinking about cancer, and if you put the information readily available to them that they could see it. I think that's a great idea."	
	"I think it's a good idea to be a potential, it's a good idea."	
	"I think that's a good thing. Yeah, because this person gets to see if I'm a good fit for that kind of a study."	
	"...if I knew I was a high risk and I could be in a trial...I think I would go for them because it's going to help me, it's going to help my health hopefully."	
	"...knowledge is power and the more knowledge I have of what is affecting me and what I can do to make things better for me is going to make things better for me as a person, as a whole, my life, my body."	
	"I'm, right now like I'm curious to register because I mean you can register, you might not get picked, if you do you can still say yes or no."	
Willingness	"Well if I'm at a higher risk for cancer, the reason would be so that I can get into the prevention trial and see what I can do to prevent it."	15 (100%)
	"So I mean if you presented it as, you know, as there being benefits to it, I might be more apt to, but if you just ask, "Can I like give away your health information?" I probably wouldn't do it."	
	"So reasons I would be willing to release is that it would help to, it would help the cancer prevention trial specialist to look at my information and then decide which trials would be best for me."	
	"So to me it is fine because again that person knows more than myself...They know better than me what can I do and not can I do. You know what I'm saying. So again as long as it's just within themselves, it's not going to any other third party or anything like that, it's fine."	
Motivators	"...to pass that information along to my family members and my friends and my patients."	14 (93%)
	"...I just not think about myself, I have to think about my children."	
	"...if you were at any type of risk, you'd want to know how to change your lifestyle so it doesn't get any worse, you know."	
	"...I'm really really interested in seeing the correlations between cancer and the backgrounds of my, not so much my gender but my ethnic background."	
	"Just, just um wanting, you know, at least my information reviewed, knowing that it would be reviewed... and they may look and see something and say you know, this might be a good study for you based on the information."	
	"...I think people would see it as a positive thing if you put that and word it properly, that, you know, we have an expert in the field that's going to walk you through this. You know, people just want a little assurance that, I think somebody cares and that they can respect them, you know for the results that they find and knowing that you're going to help them I think is the big thing."	
Barriers	"I don't know where it's going, but I don't want to be uh poked and pillled up [laughs]."	7 (47%)
	"My concern here is who is going to be this person that's going to be reviewing my personal data?"	

	Sample quotes	Number and proportion of participants expressing these thoughts n (%)
	“I want to make sure where all the information is going to. Make sure it’s all going to where it’s supposed to go and not out into the world. You know, make sure it’s a confidential database.”	
	“The reasons I would not like this so much is that I might have concerns about how secure is the secure database and is my personal health information um at risk, maybe of being hacked or is somebody else might get their hands on it and go to someplace that I might be unaware of.”	

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