Published in final edited form as:

J Cancer Educ. 2013 March ; 28(1): 43–51. doi:10.1007/s13187-012-0421-5.

Community-based Partnership to Identify Keys to Biospecimen Research Participation

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Introduction

Studies to examine potential biological and tumor variation as causal influences in disease disparities often require large cohorts of data to be successfully powered [1]. Likewise, the growing number of these studies to explore and locate genetic markers for cancer risk are creating greater local, regional and national demand for biorepository databanks. Having existing samples allows quick access for these epigenetic studies, including the National Cancer Institute/National Human Genome Research Institute's "The Cancer Genome Atlas"

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Conflict of Interest

The authors declare that they have no conflict of interest.

(TCGA)[2]. However, based on the ethnic breakdown of over 8000 samples collected and stored in this repository, it is evident that with only about 10% are non-White samples, and there is a significant need to develop steps to increase collection from minority populations [2]. A limited number of studies have explored the issues of recruitment and accrual of cases and controls to biorepository databanks and the impact this will have on the resulting science [3–7].

The use of biorepository data storage and retrieval is extremely efficient for quick access to large amounts of data. Biorepository banks generally collect biological specimens such as blood or saliva from participants in order to extract genetic, biomarkers and DNA as well as epidemiological lifestyle and behavior survey data to provide large cohorts of participants that may or may not have a disease such as cancer. In general, data collection processes de-identify participants saving specimens with some form of numerical code identifications to locate and link the survey and biological data. The analysis and reporting of data is performed in an aggregate manner with the goal to find population-based variations.

The research on perceived benefits and challenges specific to participation to biospecimen banks, prior research show varying results. There may be additional fears or concerns about access and breach of confidentiality regarding an individual's "banked" genetic material and access to this material by the government or other agencies for social control purposes[8–10]. Wang and colleagues (2001) explored general attitudes toward blood donation and storage for genetic research in the American Health Styles Survey data. Only 42% of respondents who answered these questions were in favor of both blood donation and long-term storage for genetic research, and these responses were most likely to be from higher educated, white participants and people with a positive family history of a genetic disorder [10]. Other results on barriers to participation in biospecimen banking in the U.S. suggest that minority and older adults may be less likely to participate in biobanking due primarily to unwillingness to undergo blood-draw procedures [11]. African Americans in Rhode Island voiced concerns regarding discrimination and potential for genocide following participation in a biobank, reflecting the long-standing mistrust from the public health studies at Tuskegee [12]. Slattery (2007) confirms these concerns by African Americans about discrimination, consequences of genetic testing and governmental access to genetic information [13]. However, Luque and colleagues, exploring attitudes of a diverse group of community members in southwest Florida suggest that individuals over 30 years of age were less skeptical and more favorable toward biobank participation than younger people, and that decisions may be influenced by life histories, experiences and cost- benefit perceptions[7].

The goal of this formative study was to build research capacity through a pilot CBPR activity with racially diverse community members in Niagara Falls, NY, and a local cancer center to increase mutual understanding of genetic research recruitment and biobanking in Western New York (WNY). The aim of the formative study was to assess the perceptions, knowledge and beliefs about research and biobanking from representatives of Niagara Falls, New York (NY) and from the cancer center biobanking staff to determine how these perceptions are likely to impact participation in biobanking by healthy controls. These findings were then to be used by the collaborative team to develop and pilot a community-friendly educational intervention to enhance understanding, intent and participation in the biobanking program (Reported in the companion article). The research question guiding the formative research aim was "What are the key factors among Niagara Falls residents and cancer center staff that are most likely to affect decisions to participate in research and the a biospecimen bank?" The purpose of this paper is to report the process outcomes and findings from this study to identify modifiable barriers and assets to research participation in specimen banking and create a foundation for developing testable research hypotheses for

improving the collection of specimens from vulnerable and minority populations at the community level.

Methods

This was an iterative, qualitative community-based participatory research (CBPR) design including key informant interviews and focus groups, followed by a brief community survey conducted by community partners. All participants in interviews and focus groups were asked initially for their attitudes regarding research in general, and then about clinical treatment studies in comparison with research like biospecimen banking that includes healthy people. Questions about biospecimen banking were referenced to a specific biospecimen banking program at a regional National Cancer Institute (NCI) -designated cancer center. This biorepository is a critical resource both within the cancer center and nationally (with the TCGA) for developing a foundation for molecular and genetic studies on cancer prevention and treatment [14]. For this data and sample bank; each participant responds to a 36- page lifestyle and behavioral questionnaire, and each participant donates a blood sample (up to 40ml) or saliva.

Population

Niagara Falls, NY, has a population of 50,193. Seventy-two percent of the residents are White, 22% are African American, 2% are American Indian and 3% are Hispanic/Latino [15]. Seventy-seven percent of the population graduated high school and 12.5% have a college degree or higher educational attainment. The median household income is \$26,800 and per capita income is only \$15,721. Twenty percent of the people in Niagara Falls are below the poverty level and only 57.6% of occupied housing units are owner-occupied [16].

Community Leadership Group

A community advocate from the Niagara Falls area assisted in the recruitment of representative members from the Niagara Falls community to serve on a Community Leadership Group committee. The purpose of the Community Leadership Group was to serve as collaborative community-based investigators with the cancer center study staff. This ensured that the aims, methods and analysis of results of any study activities reflected the concerns, knowledge and experience of people in the Niagara Falls community as well as the biomedical and scientific perspective of the cancer center. The Community Leadership Group was composed of seven members reflecting diverse demographic characteristics: three African American, four White; four women, three men; and employment including community outreach, sales associate, artist, child care, and a city council representative. These group members were recruited from the patient population at the community health clinic, a community outreach program at the local hospital, and city council membership. Community Leadership Group members were paid honorariums for their time over the course of the study and completed the Human Subjects Protection Course (CITI on-line training). They also agreed to participate in Key Informant interviews and recruited and scheduled participants for two focus groups and the community survey in Niagara Falls.

Key Informant Interviews

Key Informant interviews for this study were nine open-ended, semi-structured interviews with seven Community Leadership Group members of the Niagara Falls community (recruitment described above) and two cancer center staff involved with the biorepository process. The questions were tailored differently for community members and cancer center staff. The interviews were done with the Community Leadership Group members before they were recruited to serve on the study committee, and the debriefing from this interview

served as an introduction to the study and recruitment to work with the study staff to conduct the rest of the study. In addition to the topical questions (see Table 1), demographics for each participant was collected.

The purpose of the interviews was to obtain perspectives from representative community members and cancer center staff about global issues related to research and to solicit any information from them regarding their understanding of the difference between clinical treatment studies and biospecimen collection for future research. In particular, we wanted to collect attitudes about factors that might impact participation in various forms of cancer research in order to find key issues that can be incorporated in a recruitment intervention and focus group questions. Based on these findings, we were to define and identify the specific questions and educational concepts that needed to be addressed regarding biobanking research in the pilot study. Following the collection of all Key Informant interviews, the Community Leadership Group members decided that many of the same questions used for the interviews were appropriate and should be used for the focus groups to gather a wider discussion on these topics.

Focus Groups

Three focus groups were conducted—two in Niagara Falls, NY, (one with African American residents and one with white residents), and one with cancer center staff working for the biorepository and its recruitment. The literature suggests that there are variations in attitudes and beliefs about biospecimen banking among different racial and ethnic groups so we segregated our groups by race [3, 8, 11, 13, 17]. The Community Leadership Group members decided to recruit and conduct the two focus groups to be homogenous by race and led by race-concordant facilitators in order to provide an environment for optimal ease of discussion. The first focus group, held at the local library, included white residents, recruited by Community Leadership Group members from local city committees, churches, and work-affiliated unions. African American participants were recruited from advocacy groups, city committees, and area churches in Niagara Falls, and the focus group was conducted at the local community center.

A user-friendly approach for obtaining quantitative data at focus groups was done through the use of Microsoft PowerPoint slides and an audience response system (ARS) using electronic keypads [18, 19]. The ARS was used for obtaining quantitative “yes/no” or multiple-choice responses, such as willingness to participate; experience or prior participation in research, and all demographic information (see Table 1). Both the quantitative questions (e.g., would you be willing to donate blood..?) and the open-ended questions in the focus groups allowed for group discussion and interplay among participants about the specific research topics. Open-ended questions included various prompts for further discussion adding depth of meaning (see Table 1). Focus groups lasted approximately an hour and a half and participants were offered refreshments but were not paid to participate. The goal of the focus groups was to create an inventory of issues and factors to formulate the development and conduct of an educational intervention to inform potential participants about biospecimen and biobanking donation. All participants in both the focus groups and interviews granted oral consent through the use of an Information Sheet, as all data was collected anonymously.

Community Surveys

Following participation in the Key Informant interviews and review of the focus group responses and data, the Community Leadership Group wanted to know more about the attitudes of people in their community about research and potential venues for the educational programs and they proposed to conduct their own survey. They created and

conducted a 22-item community survey using a convenience sample from local malls, health fairs and community festivals over three weeks (see Table 2). These data were expected to reflect the views of potential participants to future educational programs from a larger sample of community members to prepare for pilot study.

Analysis

The focus groups were recorded and study staff reviewed the audiotapes and notes from the focus groups and typed these into a text-based analysis program (Sphinx). ARS responses for quantitative questions were downloaded into a data dump and SPSS analysis was used to develop frequencies and descriptive statistics. The Community Leadership Group and academic study staff reviewed all of the text and resulting frequencies together, sorted and coded text for thematic content. These were organized into categories reflecting barriers and negative perceptions, assets and positive experiences, variations by race, and variations between community and cancer center perspectives. All study activities were approved through the NCI -designated cancer center's Human Subjects Institutional Review Board

Results

Table 3 displays demographic variables for participants from the Key Informant interviews (n=9), focus groups (n= 26), and community surveys (n=64). Approximately 57% of Niagara Falls participants in the focus groups and community surveys had household incomes above \$30,000 (the median income is \$26,800, and per capita income is only \$15,721). Educational levels were equally distributed across all levels, with 29% having attained a high school degree, GED or less and 34% of Niagara Falls participants having a college degree or graduate school experience (compared with only 12.5% in the Niagara Falls community as a whole). These participants represented a higher proportion of African Americans and more of the Niagara Falls residents with more years of education and somewhat higher incomes than the average resident per the census figures at the time. Conducting the focus group and community surveys and drafting questions and survey instruments provided the Community Leadership Group the opportunity to increase their direct experience and understand the role of mechanics of an Institutional Review Board and the research process.

Key Informant Interviews

Of the seven Niagara Falls community members completing Key Informant interviews, six had had a family member or close friend diagnosed with cancer, three reported having signed a consent document for a clinical treatment study before, two did not know if they had ever signed a consent, three were very familiar with "something called a clinical trial or clinical study" and three were not familiar with these types of studies. The following selected responses from Niagara Falls interviews were considered important to address in research recruitment: (1) Factors reported to positively influence participation in research in general: *"Money" or "financial incentives"* (three individuals); *"...Make a person feel good about themselves..."* *"...help humanity"* [altruistic] (two individuals); *"If a person I know is recommending it [I would be more likely to participate]"* (three individuals); and *"...if a person serves as a role model...someone who has been involved in the study before... [I would be more likely to participate (one person)."* (2) Factors that negatively influence participation: *"Inconvenient ... not having time or able to leave your job..."* (three individuals); *"Distrust of doctors...Big Brother aspect of pharmaceuticals"* (two individuals); *"Afraid to take something that could put me at more risk..."* [fear-related responses (three individuals); *"There's a power issue -people having power over you"* (two individuals); concerns about being a *"guinea pig"* (three individuals). (3) Factors influencing who participates in research studies and why: *"People with time on their hands. Retirees"*

(one person); “...*More of a risk taker...*” (two individuals). The following responses from the biobanking staff interviews were considered important to address by health institutions involved in research recruitment: (1) Factors influencing negative issues regarding participation in the biospecimen and data banking program: “*I know there are concerns that...their information is going to be sold to insurance companies, influence their employment and that the information will be used in a negative way.*”; “*If the process is sloppily done, poorly managed ...or people get hurt or sick [they will not want to participate in the future or deter others.]*” (2) Factors influencing positive issues regarding participation in the biospecimen and data banking program: “*If you can approach people with the time and ability to participate...not too tired or sick.*”; “*... the [positive] reputation of the group [doing the study].*”

Focus Groups

In the focus group of seven white community members, all participants reported having a family member or close friend with cancer. Six participants had never signed an informed consent for a study, one person reported not knowing if they had ever signed a consent form. Four participants reported being “somewhat familiar” with a “clinical trial” and the other three were not familiar with the term. Most notable in the group discussion about research were comments about advertising and issues with drug development and the pharmaceutical industry: “*...drug companies-- I don't believe them...*” “*I wouldn't want to participate in anything that was done by the drug companies because it's just going to benefit them.*” As none of these participants had personal experience with a clinical study, their primary research experiences and perceptions included what they had heard on television and the testing of drugs for profit by the pharmaceutical industry. The participants were consented to the study and knew that this focus group was conducted under the auspices of the regional NCI-designated cancer center. One gentleman stated that “*I'd be much more likely to participate in a study sponsored by [cancer center] than a drug company because the drug company is just going to exploit you or the situation to make money.*” Upon further discussion, several participants stated personal experiences with the local cancer center that resulted in positive beliefs about the nature of research, particularly research conducted at the cancer center because it was focused on “*finding better ways to help people*” and “*reduce suffering with cancer.*” Several participants reported fears of taking drugs, the “time away from work” required to participate, general fears of “needles, keeping my DNA, blood testing/blood draws,” and whether “needles would be clean.” One participant stated that she would expect “[cancer center] to conduct safe research.”

The participants were aware of and commented on the local *Love Canal*¹ health crisis and the toxic waste problems in their region and immediate neighborhoods [20]. The participants in our focus groups considered themselves to have been exposed to numerous carcinogens and that “*everyone in Niagara Falls was at risk for cancer.*” This belief was further reinforced by the fact that all participants reported cancer in a family member or a close friend/coworker. They also were experienced with numerous surveys and assessments of risk related to industrial waste and toxins and many had participated in community risk and exposure assessments.

¹ Love Canal was an unfinished canal and land region in the Niagara Falls NY area that was used to dump an estimated 22,000 tons of mixed chemical and hazardous wastes from 1942 to 1953, then covered with dirt and declared safe. This land was sold in 1955 to construct an elementary school and housing development. Unusually heavy rain and snowfall in 1975 and 1976 caused the previously buried biohazardous chemicals and waste to permeate the soil and drinking water in the area, and in 1978 it was declared a threat by the New York Department of Health Commissioner. Families were evacuated, lawsuits were subsequently filed, and subsequent chromosome damage in residents was discovered.

Responses to factors that may help increase participation in research included issues related to time and work schedules: *"Time—keep to a certain time limit, like 2- v. 4-months on a study; the shorter the better;" "People who work need to be compensated for their time ... transportation -- some people let you take time off from work."* One member in the group suggested having a *"lab scientist come talk to people in the community and tell them those stories... [about the uses for the biobanking program]."* Most of the White participants thought that most study participants were middle-aged "white folks" and college students. Money or financial incentives was only mentioned once when the question was asked, "Who participates in ... studies? *"People make money off studies, like giving plasma...."*

In the African American focus group, 14 participants had a family member or close friend who had had cancer. Four participants reported signing a consent for a study, eight had not and two didn't know. Eleven participants reported being unfamiliar or never having heard of a "clinical trial." All of the participants in this group agreed that money was a factor in "reasons for participating" or influencing a person to participate: *"People in our community go for extra money."* Their experience or knowledge about research included, *"college students doing it for the money."* Participants reported that being compensated for participating would help increase accrual of African Americans. The discussion and interaction among participants included many comments about the pro's and con's of people being paid for donating blood or plasma, or for participating in studies. Questions about the differences in these donations and blood donations for genetic analysis for biobanking did not promote responses that demonstrated a differentiation between donating specimens for blood bank purposes and the donation of individual genetic material for long-term banking and research. Even with prompts about "future research," there was little discussion regarding the risks or issues of banking genetic materials.

Regarding questions about why people do or do not participate, the discussion and comments focused heavily on mistrust and not wanting to be *"experimented on."* The term "guinea pig" and discussion about the "fear of being experimented on" were mentioned by all the African American participants in this group and were mentioned in discussion of three focus group questions (Questions #14, #18, #19, Table 1). The primary reason for a person to participate in research was, *"last alternative for prolonging life,"* reflecting the more common perception of phase 1, clinical treatment studies for diseases not cured through standard treatment. Prompts regarding the difference in medical treatment studies and tests on healthy people (Question #24 Table 1) did not promote very many comments or discussion. Few participants seemed to understand the concept of biobanking and using genetic material for epidemiological research. Upon further explanation, participants understood the concepts of using research to discover the causes of cancer, but did not link it to collecting biospecimens from cancer patients and healthy controls. There were comments about the fact that African Americans should be part of the process and recognition because *"cancer affects all races of people."* African American participants reported that they believed that most of the participants on any types of studies were college students and African Americans who were doing it for the money.

The biospecimen banking staff focus group had younger participants than those conducted in the community. Three participants had a family member or close friend who had had cancer, three had signed consent for a research study and, as would be expected, all were very or somewhat familiar with clinical studies. The biospecimen and data banking program staff focused their group discussion more on the details of research, the consenting process and the challenges of recruiting patients, as their primary experience with research was from the work environment. From their experiences within the cancer center recruiting patients (cases) and friends and family members who come to the cancer center with the patients (controls), the biospecimen and data banking program staff had an extensive list of reasons

why patients do not participate, including the following: *“Problems with logistics;” “extra trips to the [cancer] center;” “inconvenient physical challenges;” “filling out forms and paperwork, people calling you...;” “They may overly trust or distrust you;” “There are beliefs about the government... paranoid;” “... ..refuse to participate because they don’t want anyone to have their DNA;” “... always a risk to giving your identity and information...” “Everything is built on stewardship and trust.”* They discussed the variation in types of research participation (e.g., clinical treatment v. epidemiological), and one participant noted that there was *“less stress from a blood draw than from completing those questionnaires — especially for men.”* With regard to reasons people are more likely to participate, one staff member noted that, *“People are more likely to participate if they are personally interested in the research question —like weight loss. Because they have a personal interest in weight management medically, they think it will help them, so they are vulnerable [and willing to participate].”*

Community Surveys

The 64 community survey answers showed a moderate likelihood that respondents would participate in a cancer prevention study (33% likely or very likely); a majority (61%) was likely or very likely to complete a survey of lifestyle and diet; and 39% were likely or very likely to participate in a study that included giving blood.

Discussion

The qualitative study findings demonstrated that to recruit diverse community members to participate in biospecimen banking we should 1) Carefully craft the educational and promotional plan to meet specific needs within our community; and 2) Demonstrate that the study includes credentialed scientists and trusted institutions to reduce fears of exploitation. Regarding preparation of participants and promotion of biobanking, there is a need to clearly educate participants about the nature and conditions of a study and what is involved in participating because many people do not understand research well in general, and their decisions need to be based on specifics of the study. The African American community members in our study demonstrated less understanding of the use and nature of prevention or biospecimen procurement for research. Likewise, they were more likely to report concerns of research exploitation (e.g., being a “guinea pig”), while white respondents expressed considerable concern about being exploited for money by for-profit businesses. There was more discussion by African American participants regarding the appropriateness of paying individuals for participating than there was among white participants although both discussed this issue. This is an area that suggests a need for further research as the utility and impact of financial incentives for biobanking remains unclear. Interestingly, the community survey results suggest that a minimum of 30% of Niagara Falls residents would consider participating in the biobanking process. Greater education and knowledge transfer about the nature and benefits of biobanking and research contributions may potentially enhance willingness to participate.

Secondly, regarding study “credentialing,” the discussions suggest that including cancer scientists and clinicians from a respected cancer institution to demonstrate passion, commitment, and reason for trust can be a potential strength for biobanking. As discussed by Wood and colleagues (2010) related to online consent processes in the U.K., “authenticity and credentials” for any study is an essential basis for trust by potential participants. In the findings presented from this study, it is clear that the reputation of the cancer center provided support for research linked to that institution—particularly for the white residents [9]. Promoting studies that are designed by and benefit local cancer scientists/clinicians, not pharmaceutical companies may help reduce concerns about “exploitation,” although it may be necessary to discuss the conditions under which the institution itself may benefit from the

use or storage of biospecimens. Transparency about how blood specimens or information are to be used by study sponsors, specifically addressing the issue of profit, needs to be addressed in the consent of a study. Based on these findings, future research should explore the function of money— both for participants, and profit-motive for institutions-- as motivating incentives to participate in research and promote research, respectively. Although limited in scope, these formative findings are important contributions to the development of effective recruitment methods and programs to educate potential participants about biospecimen banking.

A strength of this study is the purposeful inclusion and oversampling of African American community members and the ability to develop and mobilize a Community Leadership Group for the purposed of conducting research and facilitating education.

A limitation as well as important caveat to this study is the fact that at least some of the results from this formative research reflect issues that may be specific to Niagara Falls and Western New York (e.g., concerns of toxic exposure and cancer risk increasing interest in research involving genetic specimen collection, positive reputation of the cancer center as a focus for research v. concern of pharmaceutical exploitation). The industrial toxin history and 100+ years of a scientific cancer research environment in this region may be unique or reflect issues inherent in the Great Lakes and northeastern U.S. Scientists and community members need to document the *local* variation of known factors, such as medical mistrust and fear of being a “guinea pig,” and other perceptions and beliefs that impact vulnerable individuals’ decisions to interact with the local clinical and research community.

This study further supports the use of a CBPR orientation to forge important links between scientific mission and the individual needs and problems of vulnerable communities by creating working, power-neutral collaboration with the community to study and enhance the inclusion of diverse populations in biospecimen repositories [7]. From the analyses of these findings, the Community Leadership Group and study staff created a one-hour program to be delivered by a PowerPoint presentation to educate community residents about the issues, risks and benefits of biospecimen banking. This educational intervention served as the pilot to be tested in the second phase of our study to determine the impact of this process for recruiting to the local biobanking program (see companion article in this journal).

Acknowledgments

The authors would like to thank E. Cohen, P. Posey, O. Steed and A. Primus of the Community Leadership Group in Niagara Falls, NY, and Detric Johnson, Paula Jones, Margaret Zuppa and Mary Nesline for their assistance in this research and review of this article. This study was funded by Roswell Park Cancer Institute Alliance Foundation and NIH Partners in Research Program grant R03CA139946 from the National Cancer Institute. The Roswell Park Cancer Institute DataBank and Biorepository is a CCSG Shared Resource supported by P30CA016056-27. Marc T. Kiviniemi’s work on this project was supported by NIH grant K07CA106225. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Cancer Institute or the National Institutes of Health. Sections of this manuscript were presented as a poster, at the American Association for Cancer Research (AACR), Disparities Symposium, February 3–6, 2009, in Carefree, AZ, and as a podium presentation at the International Cancer Education Conference, September 8, 2011, in Buffalo, NY.

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Table 1**Study Questions**

Key Informant Interview Questions ^a	
Q1	When I say the word “Research,” what do
Q2	What personal experiences or stories from other people have you heard about research involving people, like medical or treatment studies?
Q3	Why do we do research?
Q4	What are all the reasons that you can think of for people to participate in a medically-related study?
Q5	What are all the reasons that you can think of for people NOT to participate in a medically- related study?
Q6	What are all the factors you can think of that may influence a person to participate in a study?
Q7	Who do you think participates in clinical or medical studies? What kinds of people?
Q8	What would it mean to all people in the United States if studies were carried out with just one gender or just one race or just one ethnic group?
Q9	How is a medical treatment study for people with a specific disease different than a study that may take blood or tests something on healthy people any diseases yet?
Q10	What is different about the way you would recruit people for these two studies?
Q11	What are the factors within specific subgroups of the Western New York area that are most likely to affect people’s decisions to biospecimen and data banking program?
Focus Group Questions	
Q12	Have you or any of your family members ever signed an informed consent paper to participate in a clinical treatment trial?
Q13	How familiar are you with something called a “Clinical Trial” or “Clinical Study”?
Q14	When I say the word “research” what so you think of?
Q15	What personal experiences or stores from other people have you heard about research involving people, like medical or treatment studies?
Q16	Why do we do research?
Q17	What are all the reasons that you can think of for people to participate in research or medically-related study?
Q18	What are all the reasons that you can think of for people NOT to participate in clinical research or medically-related study?
Q19	What are all the factors you can think of that may influence a person to participate in a study?
Q20	Who do you think participates in clinical research or medical studies?
Q21	Who do you think participates in clinical research or medical studies?
Q22	What would it mean to all people in the United States if studies were carried out with just one gender or just one race or just one ethnic group? How would you change that?
Q23	How is a medical treatment study for people with a specific disease different than a study that may take blood or tests something on healthy people that don't have any diseases yet?
Q24	Which term do you prefer? For a study of the outcome of treatment(s) on a patient with a disease?
Q25	Which term do you prefer? For a biological differences in healthy people?

^aQuestions were only asked for cancer center staff participating in the key informant interviews and focus group.

Table 2

Community Survey Questions

<i>Questions</i>	
Q1	How likely are you to participate in a cancer prevention medical study?
Q2	How likely are you to participate in a cancer prevention medical study that will pay you money?
Q3	How comfortable are you completing a survey about your lifestyle and diet?
Q4	How likely are you to donate a blood sample for a cancer prevention medical study?
Q14	What would prevent you from participating in a cancer prevention medical study?
Q15	What would interest you in participating in a cancer prevention study?
Q16	When I consider the advantages and disadvantages of participating in a cancer prevention medical study that includes donating blood, how do you feel?
Q17	When I consider that advantages and disadvantages of participating in a cancer prevention medical study that includes completing a survey about lifestyle and diet, how do you feel?
Q18	When I consider that advantages and disadvantages of participating in cancer prevention medical study that pays \$10–25, how do you feel?
Q19	Have you ever been asked to participate in a medical study before?
Q20	Have you ever participated in a medical study before?
Q22	Would you be interested in attending a program that features cancer doctors and scientists discussing research and informing you about opportunities to participate in research?
Q23	How did you receive this survey?
Q24–32	Demographic questions that included age, race, marital status, gender, zip codes, household income, employment status, insurance status, and education

Table 3

Formative and Qualitative Study Participants

<i>Participant Demographics</i>				
	Community Focus Groups (n=21)	Staff ^a Focus Group (n=5)	Key Informant Interviews (n=9)	Community Surveys (n=64)
Gender				
Male	13	1	4	31
Female	8	4	5	30
Missing				3
Type of Health Insurance				
Medicaid	1		1	2
Private health insurance or HMO	16	5	6	40
Medicare	3		1	11
No insurance	1		1	6
Other				1
Missing				4
Last Year of School Completed				
Less than high school				5
High school graduate or GED	7			12
Some college or technical school	10	1	3	19
College graduate	3	3	1	16
Graduate School	1	1	4	10
Missing			1	2
Marital Status				
Married or living with a partner	15	3	5	31
Divorced or Separated	4		1	6
Never Married	2	2	1	19
Widowed			1	
Missing			1	8
Race/Ethnicity				
White (non-Hispanic)	6	5	7	6
Black or African-American	13			34
Mixed (non-Hispanic)			1	
Other	1		1	2
Declined to answer	1			
Missing				22
Yearly Household Income				
Less than \$15,000	5	1	1	11
\$15,001–\$30,000				9

<i>Participant Demographics</i>				
	Community Focus Groups (n=21)	Staff ^a Focus Group (n=5)	Key Informant Interviews (n=9)	Community Surveys (n=64)
\$30,001–\$45,000	4	2	3	12
\$45,001–\$60,000	5			10
\$60,000+	7	1	4	13
Missing			1	9

^aBiospecimen and Data Bank