Project ACCRUE: Exploring Options to Increase Awareness of AIDS Malignancy Consortium Clinical Trials in North Carolina

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Abstract

BACKGROUND—Longer lifespans conferred by antiretroviral therapy result in more time exposed to cancer risk for people living with HIV/AIDS (PLWHA). Given limited diversity in AIDS Malignancy Consortium (AMC) clinical trials, there is need for new approaches to educate PLWHA in order to improve awareness and participation in AMC trials.

METHODS—With input from a community advisory board, Project ACCRUE (AMC Clinical Trials at Carolina Ramp Up Enrollment) conducted a key informant interview with service providers; online organizational surveys of AMC trial awareness and resource needs; and “lunch and learn” educational sessions, including pre- and post-intervention knowledge assessments.

RESULTS—Providers indicated that transportation, mistrust of the medical community, and affordability were barriers to trial participation, while printed educational materials could facilitate trial recruitment. Providers indicated that their clients had concerns about participating in trials, but also recognized several benefits of participation including access to medical personnel and treatment, receipt of monetary incentives, and a feeling of satisfaction from helping others. In lunch and learn sessions, use of an audience response system to collect questionnaire data improved scores on knowledge-based items \[S(55) = 460; P < .0001\] compared to a pencil and paper test \[S(20) = 12.5; P = .6541\].
LIMITATIONS—Generalizability may have been compromised by the small sample size. Long-term recall was not measured, and the short retest interval may have impacted post-intervention assessments.

CONCLUSIONS—Service providers recognize the benefits of working with researchers to educate patients about HIV-related cancers and participation in clinical trials. Lunch and learn sessions improved knowledge and perceptions about clinical trials for PLWHA.

With the advent of antiretroviral therapy, people living with HIV have experienced longer lives. Living longer is intrinsically associated with increased cancer risk, and some cancers occur more frequently among people living with HIV and AIDS (PLWA) than among individuals in the general population. In North Carolina, acute HIV infection is occurring at increasingly younger ages [1], thus increasing the exposure of PLWHA to cancer risk. Creative strategies are needed to address the excess cancer burden experienced by this population [2].

PLWHA who develop cancer are 2–4 times more likely to remain untreated than are people with cancer in the general population [3]. Clinical trials provide hope for improved cancer treatment for people with HIV/AIDS. Trials not only provide state-of-the-art treatment for HIV-related malignancies but also allow researchers to ascertain new knowledge. However, clinical trial participation is limited by factors such as lack of knowledge of trials, lack of awareness that PLWHA are at higher risk for certain cancers, and lack of availability of targeted treatments for HIV/AIDS-related cancers. Community engagement and education on HIV/AIDS-related malignancies and on clinical trials are needed to increase awareness of trials as viable options for PLWHA.

Behavioral approaches are urgently needed to promote recruitment of underrepresented groups into cancer treatment and clinical trials. PLWHA who are Latino or African American are less likely to receive treatment than are whites [3, 4]. In 2011, the AIDS Malignancy Consortium (AMC), a clinical trials group sponsored by the National Cancer Institute (NCI), created an initiative with the Office of AIDS Research and the Center to Reduce Cancer Health Disparities to address the lack of diversity in AMC trials. The AMC is composed of 26 clinical trials sites in the United States and 4 sites in Africa. North Carolina is an AMC affiliate trial site, but the availability of AMC clinical trials in our state is in its infancy, and data to identify and chart trends are not readily available.

The Carolina Community Network Center to Reduce Cancer Health Disparities (CCN II) was established at the University of North Carolina at Chapel Hill (UNC-CH) to address cancer inequalities among underserved minority communities in North Carolina. In response to the call to improve the accrual and retention of underrepresented minorities in AMC trials, CCN II developed Project ACCRUE (AMC Clinical Trials at Carolina Ramp Up Enrollment). Given the scarcity of AMC trial availability in North Carolina, the goal of Project ACCRUE was to increase awareness and knowledge of HIV malignancies and AMC trials among key stakeholders and the general community.

The current article presents the results of the multiple strategies used to raise awareness and increase knowledge of AMC trials and HIV/AIDS malignancies among a diverse group of
stakeholders such as lay community members, PLWHA, leaders of agencies providing services to PLWHA, and the staff of those agencies.

Methods

Project ACCRUE ran from 2010 to 2015. Since there were no open AMC trials in North Carolina at the start of this project, an opportunity existed to cultivate future trial participation among PLWHA through educational outreach designed to increase knowledge of HIV/AIDS malignancies, identify resources needed to facilitate AMC trial participation, and promote awareness of AMC trials. An existing community advisory board (CAB) comprised of diverse individuals, including those who live with HIV/AIDS or have been affected by the disease, served as a primary stakeholder liaison between the North Carolina communities affected by HIV/AIDS and the UNC-CH Clinical Trials Unit and HIV Prevention Trials Network. Input was provided by 12 CAB members (4 females and 8 males; 5 whites and 7 African Americans; 9 with HIV and 1 with cancer). CAB members provided input on the 3 main aspects of this study: Project ACCRUE’s proposal to conduct an interview with directors of organizations providing services to PLWHA, an online survey of a broader audience of directors and staff of the organizations serving PLWHA, and lunch and learn educational outreach sessions. The institutional review board at UNC-CH approved this study and provided human subjects protection oversight.

Key Informant Interview of Directors

Directors of 2 organizations that serve PLWHA participated in a combined key informant interview designed to elicit information for revising and finalizing a draft online survey for distribution to a broader group of organizations serving PLWHA. A certified community health educator and a research associate conducted the interview using a set of thematic probes: the services provided; perceptions of clients’ knowledge about HIV-related cancers, clinical trials, and clinical trial participation; directors’ interest in partnering with Project ACCRUE to increase awareness about AIDS-related cancers and to recruit for clinical trials; directors’ confidence in performing tasks to implement a program; and organizational needs for partnering in program implementation.

Survey of Community Organizations Serving PLWHA

Directors and staff of target organizations (n = 39) in central North Carolina received an online survey consisting of 15 multiple-choice questions designed to gather information on perceptions of community knowledge of AIDS-related cancers and clinical trials, positive and negative perceptions of clinical trials, ideal methods for sharing information about AIDS-related cancers and clinical trials, and organizational needs related to educating community members about this topic. Email invitations with an introductory message were sent to organization directors asking them to complete the survey and share the survey link with other staff members. A reminder email was sent 7 days after the initial email invitation. Responding organizations that provided contact information were entered into a drawing for a free office meal.
Community Outreach Education

An educational presentation was developed to present basic cancer facts, distinguish between AIDS-defining and non-AIDS-defining cancers, present screening guidelines for cancers, and promote awareness of and participation in clinical trials. Content for the presentation was adapted from publicly available information provided through the NCI and the American Cancer Society (ACS). For example, information from the ACS’s cancer basics webpages [5] was used to define cancer and describe how it spreads. Similarly, the NCI’s website has information about cancer risk for PLWHA, reasons why some AIDS-related cancers are on the rise, differences between AIDS-defining and non-AIDS-defining cancers, ways to reduce risk through screening, and options for treatment [6]. The presentation’s content included ways to promote participation in clinical trials, reassure participants about safety and privacy protections, describe participant rights and responsibilities, and explain the importance of clinical trials.

A lunch and learn educational format was used to allow for open, informal dialogue. The CCN community partner identified organizations to host each educational session. A meal was always provided. Two educational formats were used: a traditional session and a session that included an audience response system. The traditional presentation was delivered orally within a 30-minute time frame, and it provided time for questions and discussion at the end. Knowledge of HIV-related cancers and clinical trials was assessed before and after the educational session using a 20-question, multiple-choice, pencil and paper questionnaire. All questionnaires were completed anonymously, with pre-tests and post-tests linked only by a random number that had no key.

To address perceived low literacy among the participants, the presentation format was modified by embedding the assessment questions into the presentation. Participants used an audience response system with handheld clickers on which buttons corresponded to answer choices. Audience response systems have proven useful in overcoming literacy barriers [7], making lectures more engaging [8–11], and improving knowledge retention [12]. The number of items on the pre- and post-test assessments was reduced from 20 to 16. Items that consistently received incorrect responses were removed, and a true/false format was adopted instead. In addition to questions about HIV/AIDS malignancies, questions about clinical trials were also included. The questions were read aloud as part of the presentation, and the pre-test questions were embedded in the presentation, allowing participants to respond with the clickers as the presentation progressed. Following the presentation, the post-test questions were read aloud while the participants read along on screen.

Lunch and learn questionnaire data were analyzed using Wilcoxon signed-rank tests for improvement in knowledge from pre-test to post-test. Analyses were performed using SAS version 9.3.

Results

Key Informant Interview of HIV/AIDS Organization Directors

Organization directors indicated a need for more patient advocacy and navigators to improve communication and education, and they reported that their clients assumed negative
outcomes—for example, that cancer is “supposed to happen” to PLWHA (see Table 1). Barriers to clinical trial participation included mistrust of the medical community, not having a primary care provider, problems with insurance and Medicaid, and not receiving holistic treatment. Directors stressed the importance of speaking with clients directly to learn ways of alleviating these barriers and to offer clients incentives to call the clinical trial hotline.

Directors expressed an interest in partnering with Project ACCRUE to increase awareness about AIDS-related cancers and clinical trials. Organizational needs for partnering include gas cards for client transportation, client incentives for calling the clinical trials hotline, and help for clients so that clinical trial participation could be connected with the care they are currently receiving.

Survey of Community Organization Directors

The survey was completed by 14 directors of 39 organizations serving PLWHA (see Table 2). No demographic information was collected. Because the survey asked for contact information from respondents but did not require this information, many surveys were returned anonymously, making it impossible to determine how many unique organizations were represented. Nonanonymous survey responses indicated that at least 5 organizations were represented. All respondents reported having direct patient contact.

Almost all (13 of 14) respondents indicated that, in their opinion, community members knew nothing or very little about HIV-related cancers (see Table 2). Moreover, 14 of 14 indicated that their clients knew nothing or very little about clinical trials for these cancers, although 10 of 14 respondents reported that at least 1 of their clients had recently participated in a clinical trial. Of 14 directors, 4 reported hearing fears from clients about clinical trials, such as apprehension about being a “guinea pig” or being “experimented on.” On the other hand, 9 of 14 directors had heard good things about clinical trials: they provide access to clinicians and treatment options, offer monetary incentives, and give patients the chance to help others. According to directors, the top 3 barriers to entering a clinical trial were a lack of knowledge of clinical trials in general (11 of 14 respondents), a fear of the unknown (9 of 14 respondents), and a lack of proximity to a study site (9 of 14 respondents).

All respondents indicated that hearing information about clinical trials from someone who had participated in a clinical trial would be at least somewhat useful for their clients. Other options that directors endorsed as at least somewhat useful included having written information (like brochures) that clients could take home (12 of 14 respondents), hearing information from the doctors and scientists who run the trials (13 of 14 respondents), seeing a presentation about the topic (14 of 14 respondents), and reading a blog on a website about clinical trials (7 of 14 respondents). Of 14 respondents, 9 reported knowing where to go for information about AIDS-related cancers, and 7 of 14 respondents knew where to find information about trial availability and enrollment to share with their clients.

Respondents felt their clients most needed 3 specific kinds of information to encourage participation in trials: safety information about clinical trials (12 of 14 respondents), information specific to cancer among PLWHA (12 of 14 respondents), and information
about benefits to society (9 of 14 respondents). The 3 types of resources that agencies most commonly reported they could use included information to distribute (11 of 14 respondents), a book of resources (5 of 14 respondents), and someone to call with questions (7 of 14 respondents). Respondents also indicated interest in having Project ACCRUE conduct a lunch and learn session for their clients (10 of 14 respondents) and provide brochures (10 of 14 respondents) to help them raise awareness and encourage trial participation.

Lunch and Learn Sessions

Over a period of 10 months, 9 lunch and learn sessions were held, totaling 85 participants (see Table 3). Session evaluations were completed by 77 participants: 21 for the paper and pencil sessions (4 sessions) and 56 for the audience response system sessions (5 sessions). Approximately 75% of the participants were African American; the sex ratio was almost equal for the paper and pencil sessions but was more heavily female (57%) for the audience response system sessions. Participants in the audience response system sessions were older, on average, than those in the paper and pencil sessions (mean age: 54 years versus 46 years). We did not collect data on type of residence, income level, education level, HIV serum antibody status, cancer history, or other variables that could be construed as deeply personal or compromising of anonymity.

For the paper and pencil sessions (see Table 4; online version only), no significant change in knowledge scores was noted between pre- and post-test assessments \[S(20) = 12.5; P = .6541\]. However, a significant improvement in knowledge scores was noted between pre-tests and post-tests for the audience response system sessions \[S(55) = 460; P < .0001\], although the content of the presentation was the same (see Table 5; online version only). Knowledge scores between the clicker sessions and the paper and pencil sessions cannot be compared because of notable changes in evaluation instrumentation.

Participants in both groups were also asked pre- and post-intervention whether they would participate in a clinical trial. Willingness to participate in a trial increased among participants in each type of lunch and learn session. Baseline and post-session willingness to participate in a clinical trial increased from 82% to 95% for the paper and pencil groups and from 62% to 69% for the audience response system group.

Discussion

The current study describes preliminary work to develop strategies aimed at increasing awareness and knowledge of HIV malignancies and AMC trials among key stakeholders, including PLWHA and the general community. These strategies are essential given the expressed barriers to participation in AMC trials such as lack of trial availability and the presence of few clinical trial sites beyond major medical centers. The overall number of participants in therapeutic AMC trials is generally small, as trials are typically disease-specific and therefore less broadly inclusive. Moreover, UNC-CH, the AMC trial institution in North Carolina, is not accessible to many PLWHA; North Carolina is largely rural, and transportation is a major barrier to health care in general.
Taken together, our study findings reveal a need for community-based education surrounding HIV/AIDS and cancer. In such an endeavor, research institutions should partner with service organizations to gain trust from the community and to learn about the community’s needs as they pertain to HIV-related cancer. This project highlights the need for information about these cancers to spread beyond academic institutions and to reach PLWHA so that they may be inspired to obtain care and participate in clinical trials. Service organizations and clients are eager to learn more about treating this comorbidity of HIV/AIDS, yet few know where to find this information. Although the majority of participants indicated they would participate in a clinical trial following the lunch and learn presentation, they did not know how to find out which clinical trials might be appropriate for them. Study findings suggest that increasing community awareness of these trials might increase the number of PLWHA who are able to participate.

All aspects of the study demonstrated that organizations that serve PLWHA are interested in partnerships to help increase the awareness of HIV-related cancers and HIV/AIDS-related clinical trials. To strengthen the partnership, organizations require resources such as materials to distribute, referral resources for their clients, and resources to which they can direct their questions. This sentiment was especially highlighted in the organization survey, where some respondents indicated that lunch and learn sessions were an important resource for improving their knowledge and that of their clients.

Project ACCRUE is not the only AMC clinical trials behavioral science group to implement community-based approaches to recruiting participants into trials, though it is the only project of its kind in North Carolina. While Project ACCRUE conducted a survey of service providers, a study by Burkhalter and colleagues in New York conducted focus groups to learn about the needs of AIDS service organizations in reaching out to their communities about HIV and cancer. Consistent with findings from the current study, the Burkhalter study found that both staff and clients wanted to be educated about HIV and cancer; however, the latter reported having conflicting priorities. Therefore, Burkhalter and coauthors suggested that education should be made a priority, rather than being just one more thing that organizations have to do. Organizations should be presented with data and assisted in their efforts to connect clients to clinical trials [13]. These findings are consistent with the findings of the present study, which highlights the importance of partnering with service providers to educate the community about the comorbidity of HIV/AIDS and cancer.

Organizations must be included in efforts to increase participation in clinical trials among PLWHA, especially those in underresourced communities. Clinicians and patient navigators are in a position to guide patients into appropriate trials; as such, they are important partners in increasing the number of AMC trials in North Carolina. To explore the feasibility of engaging navigators, one of us (C.M.) met with nurse navigators to present information about the role of Project ACCRUE in raising awareness and helping to recruit study participants for AMC trials. Following the presentation of Project ACCRUE findings as described in this article, nurse navigators indicated a willingness to add AMC trial opportunities to their list of options for cancer patients with co-occurring HIV/AIDS. This response indicates the utility of this study’s findings to prompt promotion of AMC trial participation.
Limitations

Limitations of this study include its small sample sizes for primary data collection efforts, lack of long-term follow-up regarding changes in willingness of lunch and learn participants to enroll in clinical trials, and lack of descriptive data for important explanatory variables such as health literacy of lunch and learn participants. The number of participants was small (n = 14 surveys and n = 1 key informant interview with 2 participants, respectively); this small sample size limits the generalizability of the findings. The findings from the audience response system session yielded significant pre- versus post-test improvement in knowledge (compared to no improvement in the paper and pencil group), but it is difficult to determine whether this change is due to differences in interactions, questions, readability, knowledge, or some other factor. Measures of readability or literacy were not included in either format; the sessions focused exclusively on knowledge acquisition. Moreover, because the pre-test and post-test were given so closely together (within an hour), there is a possible testing effect in which participants remembered the pre-test questions and answers well enough for this to improve their performance on the post-test.

Furthermore, it is difficult to determine whether the study has adequate diversity with respect to participants and stakeholders. The vast majority (approximately 75%) of lunch and learn participants were African American, so data regarding individuals of other racial and ethnic groups who attended the sessions are limited. Also, because surveys of representatives from community agencies were conducted anonymously, it was impossible to determine how many organizations were actually represented by the results. Limited diversity coupled with small sample sizes makes interpretability difficult.

Moreover, while this study consulted stakeholders at critical points in the research process, this study would likely have benefitted from more fully stakeholder-engaged approaches, such as community-based participatory research. Representatives of AIDS service organizations and other community agencies, if engaged actively in the research process, could have enriched the study by providing better context for the information being delivered, especially considering the likelihood that these representatives had already earned the trust of the community and could thus provide entrée. The study nevertheless represents an important first step in understanding multiple stakeholder perspectives concerning a unique problem impacting North Carolinians and exploring this problem’s possible solutions.

Implications for Practice

The present work describes the importance of educating PLWHA about cancers that may especially affect them. It is also critical to educate members of the community who are HIV-negative about HIV-related cancers because they can become ambassadors for health and can share the information with friends and colleagues who are HIV-positive or are at risk for contracting HIV. AIDS service organizations and other agencies serving PLWHA require resources to raise awareness of clinical trials [13, 14]; when information is presented in an engaging way using an audience response system, the lunch and learn session may be a viable strategy for reaching community members and PLWHA. Our findings also suggest
that further research is needed in larger populations to fully understand how to best engage PLWHA in research.

**Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

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TABLE 1

Major Themes From Key Informant Interview

| Theme                                                                 | |
|----------------------------------------------------------------------|---|
| Community members find out about service organizations through word of mouth. | |
| Knowledge about clinical trials for HIV-related cancers is improving because some community members with HIV have developed malignancies in the past year. | |
| There is a lot of fatalism in the community; people think negative outcomes are “supposed to happen” to people with HIV. | |
| Barriers for entering clinical trials include lack of incentives, transportation concerns, mistrust of the medical community, not having a primary care provider, problems with insurance, and not receiving holistic treatment. | |
| Participants wanted to partner with Project ACCRUE investigators and staff, and time was not a barrier (as long as they were given advanced notice). | |
| Some items that would be helpful for facilitating partnership between organizations, Project ACCRUE, and the community include a fact sheet about clinical trials and a plan for community members to incorporate clinical trial participation with pre-existing care. | |

Note. These themes emerged from a single group interview of 2 participants.
TABLE 2
Perceptions of Community Knowledge of AIDS-Related Cancers and Clinical Trials, Ways of Sharing Information, and Resource Needs of Organizations That Serve People Living With HIV/AIDS (n = 14)

| Survey item                                                                 | N   | %  | Specific response given when “Other” is chosen |
|-----------------------------------------------------------------------------|-----|----|------------------------------------------------|
| 1. How much do you think the community your organization serves knows about HIV/AIDS-related cancers and their associated risk factors? |     |    |                                                |
| Nothing                                                                     | 5   | 36%|                                                |
| A little bit                                                                | 8   | 57%|                                                |
| A great deal                                                                | 1   | 7% |                                                |
| I don’t know                                                                | 0   | 0% |                                                |
| 2. How much do you think the community your organization serves knows about clinical trials for HIV/AIDS-related cancers? |     |    |                                                |
| Nothing                                                                     | 10  | 71%|                                                |
| A little bit                                                                | 4   | 29%|                                                |
| A great deal                                                                | 0   | 0% |                                                |
| I don’t know                                                                | 0   | 0% |                                                |
| 3. To the best of your knowledge, about how many of the individuals you serve are either currently participating in a clinical trial or have participated in the past 2 years? |     |    |                                                |
| None of them (0 people)                                                     | 4   | 29%|                                                |
| A couple of them (1–4 people)                                               | 5   | 36%|                                                |
| Several of them (5–10 people)                                               | 3   | 21%|                                                |
| A lot of them (>10 people)                                                  | 2   | 14%|                                                |
| I don’t know                                                                | 0   | 0% |                                                |
| 4. Have you heard anyone share or express fears about clinical trials, negative things about people’s experiences with them, or perhaps negative rumors about what it’s like to participate in one? |     |    |                                                |
| Yes                                                                         | 4   | 29%| Fear of being experimented upon like a “guinea pig”; drugs are new and experimental |
| No                                                                          | 10  | 71%|                                                |
| 5. What about positive things? Have you heard anyone share positive experiences or say anything positive about the potential benefits of being in a clinical trial? |     |    |                                                |
| Yes                                                                         | 9   | 64%| Medicines are paid for; get monetary incentives; access to medical personnel; helping others |
| No                                                                          | 5   | 36%|                                                |
| 6. What do you think are the 3 most important things that may prevent people from joining a clinical trial for HIV/AIDS-related cancer? |     |    |                                                |
| Thinking they are not eligible                                              | 3   | 21%|                                                |
| Lack of time                                                                | 1   | 7% |                                                |
| Simply do not want to be in a trial                                        | 4   | 29%|                                                |
| Mistrust of the medical community                                          | 3   | 21%|                                                |
| Fear of the unknown                                                        | 9   | 64%|                                                |
| Stigma related to being in a trial for HIV/AIDS-related cancer              | 2   | 14%|                                                |
| Lack of knowledge about clinical trials in general                          | 11  | 79%|                                                |
| Lack of clarity regarding how trials will benefit others                    | 2   | 14%|                                                |
### Survey item

| Survey item                                              | N | %    | Specific response given when “Other” is chosen |
|----------------------------------------------------------|---|------|------------------------------------------------|
| Distance to trial center in Chapel Hill                  | 9 | 64%  |                                                 |

**7.** We are trying to develop ways of spreading positive messages about clinical trials for HIV/AIDS-related cancers. How helpful do you think each of the following items would be for raising awareness and encouraging people to join clinical trials?

| **a. Hearing information about clinical trials from someone who has participated in a trial** |
|-----------------------------------------------------------------------------------------------|
| Not at all helpful                                                                            | 0 | 0%  |
| Somewhat helpful                                                                              | 3 | 21% |
| Extremely helpful                                                                             | 11| 79% |

| **b. Having written information (like brochures) that they can take home with them**         |
|-----------------------------------------------------------------------------------------------|
| Not at all helpful                                                                            | 2 | 14% |
| Somewhat helpful                                                                              | 7 | 50% |
| Extremely helpful                                                                             | 5 | 36% |

| **c. Hearing information from the doctors and scientists who run the trials**                 |
|-----------------------------------------------------------------------------------------------|
| Not at all helpful                                                                            | 1 | 7%  |
| Somewhat helpful                                                                              | 8 | 57% |
| Extremely helpful                                                                             | 5 | 36% |

| **d. Seeing a presentation about the topic**                                                  |
|-----------------------------------------------------------------------------------------------|
| Not at all helpful                                                                            | 0 | 0%  |
| Somewhat helpful                                                                              | 9 | 64% |
| Extremely helpful                                                                             | 5 | 36% |

| **e. Reading a blog on a website about clinical trials**                                      |
|-----------------------------------------------------------------------------------------------|
| Not at all helpful                                                                            | 7 | 50% |
| Somewhat helpful                                                                              | 7 | 50% |
| Extremely helpful                                                                             | 0 | 0%  |

| **f. Other? Getting the information from their infectious disease doctors**                   |
|-----------------------------------------------------------------------------------------------|
| Not at all helpful                                                                            | 9 | 64% |
| Somewhat helpful                                                                              | 4 | 29% |
| Extremely helpful                                                                             | 1 | 7%  |

**8.** Do you know where to go to find information about HIV/AIDS-related cancers for your clients?

| Yes  | 9 | 64%  | Medical centers, hospitals, the Internet |
|------|---|------|----------------------------------------|
| No   | 5 | 36%  |                                        |

**9.** Do you know where to go to learn about open clinical trials for HIV/AIDS-related cancers that could benefit your clients?

| Yes  | 7 | 50%  | Medical centers, hospitals, the Internet |
|------|---|------|----------------------------------------|
| No   | 7 | 50%  |                                        |

**10.** What 3 kinds of information do you feel your clients most need to help them consider joining a clinical trial for HIV/AIDS-related cancer?

- Safety information about clinical trials: 12, 86%
- Information about HIV/AIDS: 0, 0%
- Information about cancer: 0, 0%
- Information specific to cancer among people living with HIV/AIDS: 12, 86%

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| Survey item                                                                 | N  | %  | Specific response given when “Other” is chosen |
|----------------------------------------------------------------------------|----|----|-----------------------------------------------|
| Ethical responsibility of the research team during clinical trials         | 2  | 14%|                                               |
| Responsibility of the patient during clinical trials                       | 4  | 29%|                                               |
| Time commitments associated with clinical trials                           | 3  | 21%|                                               |
| Troubleshooting when things don’t go as expected in a trial               | 1  | 7% |                                               |
| Benefits of the trial (directly to the patient and indirectly to society)  | 9  | 64%|                                               |
| Other                                                                      | 2  | 14%| Confidentiality measures, compensation        |

11. To engage in a partnership to help raise awareness of HIV/AIDS-related cancers and clinical trials, what 2 kinds of resources would your organization need most?

| Response                                                                 | N  | %  |
|-------------------------------------------------------------------------|----|----|
| Staff training                                                          | 3  | 21%|
| Informational materials (pamphlets, “goodies,” etc) to distribute       | 11 | 79%|
| Educational sessions/training for the community                         | 2  | 14%|
| A book of resources that you can use or to which you can refer people   | 5  | 36%|
| Someone you can call to ask questions                                   | 7  | 50%|
| A list of funding opportunities for organizations like yours            | 0  | 0% |
| Other                                                                   | 0  | 0% |

12. How can we (Project ACCRUE) best partner with you and your organization to raise awareness about HIV/AIDS clinical trials and encourage people to participate? (Select all that apply.)

| Response                                                                 | N  | %  |
|-------------------------------------------------------------------------|----|----|
| Lunch and learn presentations by Project ACCRUE about HIV/AIDS and related cancers | 10 | 71%|
| Information (eg, brochures) that you can give to your clients to tell them about our organization and about clinical trials | 10 | 71%|
| Other                                                                   | 2  | 14%| Webinars, phone meetings |

*a Some respondents selected more than 3 answers for this question.*
TABLE 3
Participant and Site Characteristics of the Lunch and Learn Sessions by Type

|                      | Paper and pencil (n = 4 sessions) | Audience response system (n = 5 sessions) |
|----------------------|-----------------------------------|------------------------------------------|
|                      | n = 21 participants               | n = 56 participants                      |
| Mean age (in years)  | Range: 25–64                      | Range: 23–84                             |
|                      | 45.76 (SD = 3.11)                 | 54.15 (SD = 15.07)                       |
| Race/ethnicity, % (n) |                                   |                                          |
| African American     | 76% (16)                          | 74% (37)                                 |
| White                | 9.5% (2)                          | 14% (7)                                  |
| Latino               | 0                                 | 6% (3)                                   |
| American Indian      | 9.5% (2)                          | 0                                        |
| Other                | 5% (1)                            | 6% (3)                                   |
| Sex, % (n)           |                                   |                                          |
| Female               | 45% (9)                           | 57% (31)                                 |
| Male                 | 55% (12)                          | 43% (25)                                 |
| Host sites, n        |                                   |                                          |
| Housing community    | 1                                 | 0                                        |
| Church               | 0                                 | 3                                        |
| Community organization | 3                      | 0                                        |
| Clinic               | 0                                 | 2                                        |

Note. SD, standard deviation.