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Increasing Asian American participation in clinical trials by addressing community concerns

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Abstract

Background—Asians Americans are underrepresented in clinical trials, but little is known about the factors that contribute to clinical trial participation in this population.

Purpose—The purpose of this study was to identify knowledge, barriers, facilitators and cultural influences on participating in clinical trials among three Asian American ethnic groups. Concurrently, we sought to identify mechanisms and messages to facilitate dissemination of information and to identify strategies to promote clinical trial participation in this population.

Methods—Eight focus groups were conducted (n=103) with Chinese (4 groups), Korean (2 groups), and Vietnamese (2 groups) Americans. Each group was conducted with a moderator and a translator using a standardized guide.

Results—Participants discuss the benefits of contributing to science, future generations and their families by being in clinical trials. Some participants think clinical trials would give hope to those with terminal illnesses. A doctor's recommendation, being sick and needing more options for treatment are motivators for Asian Americans. Having some guarantee of treatment effectiveness and lack of side effects facilitates participation. Cultural or religious beliefs are not believed to prevent clinical trial participation.

Limitations—This qualitative, two-site study included 3 Asian American ethnic groups and is not meant to establish prevalence of beliefs.

Conclusions—Asian Americans need more information about clinical trials and their benefits to science and the larger community. Healthcare providers can play pivotal roles in enhancing recruitment of Asian Americans. Basing recruitment goals on percentage representation in most US geographic areas does not provide sufficient numbers to allow for analysis of minorities like

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Asian American groups. The discovery of important group-specific harms and benefits depends on greater participation of racial/ethnic subgroups.

Keywords

Clinical trials; Asian Americans; recruitment; cancer

Introduction

Clinical trials are important for identifying and evaluating the effects of new technologies, programs and treatments on health outcomes, especially for growing populations.[1, 2, 3, 4] The recruitment to clinical trials of racial/ethnic minorities generally, and Asian Americans specifically, is low. In a meta-analysis of 30 years of minority participation in randomized controlled trials (RCTs) for cardiovascular disease, of the 45 trials identified only 11 reported participants' race.[5] Of these 11 studies, four reported including Asian Americans with percentages ranging from 1.4 to 5%. Similarly, in a review of panic disorder community trials 21 of the 47 reviewed studies reported minority inclusion.[6] Of these studies, 8 studies included Asian Americans which comprised only 1.1% of recruited participants (range 0.4 to 5.5%) for a total of 31 participants (range 1-14). A systematic review of RCTs for obsessive-compulsive disorder identified 40 RCTs of which 21 provided ethnic/racial participation data. Twelve of the 21 studies reported Asian American rates of 0.6-17.5% (numbers range from 1-11).[7] In a systematic review of Community Based Participatory Research studies, 17 of 19 reported minority participation. Only two of these studies included Asian participants (one with 100% and one with 1%).[8] In 10 sites reporting population and recruitment rates for the Prostate, Lung, Colorectal and Ovarian screening trials, overall 3.6% of participants were Asian Americans although they represented 5.4% of the population.[9] Nine of the 10 sites reported from 0.1 to 3.6% Asian Americans and one reported 43% Asian/Pacific Islander participation when 72.9% of the local population was eligible. Such low rates of participation preclude reporting trial outcomes for subgroups.[5, 7]

Asian American communities have low knowledge of and negative attitudes toward clinical trials.[10, 11] In one study of Asian American cancer patients, 62% reported no knowledge of clinical trials.[12] In these studies, facilitators of interest in clinical trials included a recommendation by a trusted health care provider, materials available in their own language, a supportive family, and good doctor-patient communication, sensitive to cultural beliefs.

In a survey study of cancer patients and healthcare providers, Asian Americans were less likely than other groups to have heard the term “clinical trials,” to know someone who had participated in a RCT, and to be willing to participate in a RCT.[13] These respondents were more likely to think of RCTs as experiments and were concerned about insurance coverage and costs of care. To better address health disparities, public health efforts need to foster a greater understanding of the factors that may motivate or impede Asian Americans' participation in clinical trials.

Asian American community's values and knowledge about clinical trials have not been fully explored.[12] The purpose of this study was to identify knowledge, barriers, facilitators and cultural influences on participating in clinical trials among three Asian American ethnic groups. Identifying mechanisms and messages to facilitate information dissemination and promotion strategies to improve clinical trial participation was a goal.

Methods

Participants and Instrumentation

Chinese, Korean and Vietnamese communities were selected because they are primary target audiences for the Center for Asian Health. The Center for Asian Health has long standing community partnerships with the Asian Health Coalition, a network of approximately 100 agencies serving the Asian American catchment area. Partner agencies who volunteered had capacity to recruit sufficient focus group numbers and identified at least 2 community members willing to help with recruitment and implementation.

Churches, community centers and others publicized the focus groups by making announcements from community leaders, handing out flyers, and promoting “word of mouth.” Participants were paid $15.00 each plus refreshments and a raffle drawing. Each organization received $200 for assistance recruiting and hosting focus groups. From November 2011 to February 2012, purposive sampling was used to recruit 103 adults for one of eight focus groups in the New York and Philadelphia metropolitan areas. Chinese participants (n=55) were recruited from both cities. Korean (n=18) and Vietnamese (n=30) participants were recruited from Philadelphia.

All investigators, including the moderator, completed training in focus group methodology. To review studies on improving clinical trial participation, modify the protocol and create the moderator guide, the research team and community collaborators met twice to identify issues related to clinical trials and to discuss cultural concerns unique and common to Chinese, Korean and Vietnamese communities. The team slightly modified demographic measures previously used by the Center for Asian Health and translated in native languages [Chinese (Mandarin), Korean and Vietnamese] and English versions to confirm the translation and back translations and verify balance. The final moderator guide focused on cancer screening, clinical trials, and biospecimen banking (Table 1). The moderator, note-takers, and research staff attended a second workshop to review implementation of the final protocol.

Implementation

The Chinese moderator and a translator (Vietnamese and Korean groups) conducted focus groups in community settings with community partners. Institutional Review Board review and approval was gained from Temple University as part of a larger study. [14-17] Focus groups were conducted at local community-based organizations and churches. The length of discussion varied from 90 to 150 minutes. The focus groups that were conducted with Chinese American participants used Mandarin for discussion. Korean and Vietnamese American focus groups used English as the primary language with interpreters. Notes were taken in both English and the native language, and the discussions were audio-recorded.

At the beginning of each focus group, the study was explained to participants, questions were answered and consent forms were signed. Focus groups were moderated by one Asian

American investigator. At the beginning of each focus group, participants were asked to complete a quantitative survey that included demographics and participants' assessments of their knowledge of clinical trials. Demographics included: the year participants were born, their gender, whether or not they were born in the US, their ethnic background (Chinese, Vietnamese or Korean), their marital status, education (elementary school or less, some high school, high school graduate, some college and college graduate and above), employment (employed, unemployed, retired, homemaker, or student), and how well participants' spoke English. The quantitative survey also asked about access to medical care including questions for whether or not participants had medical insurance or a regular physician to visit. Participants were asked, “Do you know what a clinical trial is?” Possible responses were “no”, “know a little/heard about it,” “know some,” and “know well.”

Data Analysis

The brief survey of quantitative items was examined using Chi-square and Pearsons' correlation. Some categories were combined to minimize cell sizes under five. Logistic regression was also used to identify significant results taking into consideration the other variables in the model to counteract multiple comparisons. All variables identified as significantly related to the dependent variable (Table 2) were included in multivariate analyses. However, because one variable, education, remained in the model, only the bi-variate results are displayed.

Recorded tapes were transcribed verbatim and translated into English by a native speaker. Themes were identified independently by two coders, one a member of the research team and one a newly hired research assistant. Some themes emerged from the data like the theme, “making contributions to science.” Other themes were responses to moderator guide questions such as asking if there were cultural or religious beliefs that would encourage or discourage participation in clinical trials. Questions of translation were referred back to the native speaker and checked against the original tapes.

Once agreement on themes was reached, one member of the research team coded 100% of codable text and the research assistant double coded almost half (49%) exceeding the minimum standard for intercoder reliability of 10% for double coded text.[18] Codable text excludes expressions like laughter and inaudible phrases. Inter-coder reliability and gender differences in the number of participant comments were assessed. Excellent agreement (95%) was found. Areas of disagreement were reviewed and consensus was arrived at through discussion between the two coders. Male participants made up 40% (range 16%-73%) of comments in the groups, which closely matched their percentage representation in the focus groups that included males. Although the coders looked for differences in the presence of themes across all eight focus groups, no differences were found including those by race/ethnicity.

Results

Survey Results on Knowledge of Clinical Trials

Participants were on average 64 years of age, primarily female, married, retired, born outside of the US, and had a high school degree or above (Table 2). One group had no male participants. Most participants reported that they lived in the US an average of 22 years and spoke English “not well.” Most participants had health insurance (85%) and a regular doctor (89%). A large proportion of participants reported that they knew nothing (61%) or a little (25%) about clinical trials.

Some significant differences (Table 3) were identified for ethnicity with Vietnamese groups reporting lower levels (15%) of knowledge of clinical trials compared to Korean (66%) and Chinese (46%). Those with higher levels of education and fluency in English reported more knowledge of clinical trials. No relationship was found between knowledge of clinical trials and gender, country of birth, number of years lived in the US, age, marital status, employment, and having a regular physician. Surprisingly, those who had health insurance reported significantly lower knowledge of clinical trials (37%) compared to those without health insurance (64%). Because of the skewness in reported knowledge of clinical trials, logistic regression was used to analyze those who reported knowing nothing versus a little to a lot of knowledge. Only education remained significant in the multivariate analysis Results are reported without adjustment in Table 3.

Identified Focus Group Themes

Table 4 includes a summary of identified themes and example quotes. “Giving Hope” was identified as a key factor that may motivate participation in clinical trials. Participants discussed clinical trials as providing an opportunity to gain access to new treatment options. Many thought that those in the last stages of a disease progression would be most interested in a clinical trial. But some participants thought that patients would want some information about already identified lack of side effects and health benefit although they did understand that there were many unknowns including risks and benefits. Some participants were under the misunderstanding that the non-experimental arm of a clinical trial would only be a placebo. Participants seemed unaware of the benefits of standard care for those in treatment and that clinical trials extend to health promotion and early treatment. Disagreement existed about the influence of incentives as some thought offering incentives was critical and others thought that most people would forgo incentives. Many participants were interested in contributing to science and to giving future generations better treatment options, another kind of hope. Medical doctors and health care providers were mentioned as key advisors for patients and family with some saying doctors played the most important role in decision making. Some concerns were voiced about a lack of trust in health care providers. Participants wanted full disclosure and more information about the consent process. They were afraid that health care professionals might exert pressure to be in a trial and they also noted that doctors were not always right. Participants were most comfortable with a doctor of the same nationality and/or one who spoke their language. Religion was described as not having an influence on decision making for clinical trials although participants later reflected that some beliefs may have both positive and negative effects. Cultural beliefs like

Yin Yang and balancing hot and cold also were not seen as influential over decisions. Participants had many questions about clinical trials and suggested ways to promote clinical trials in the community. See Table 4 for a list of these suggestions.

Discussion

Most of the comments that patients had about reasons for or against participating in clinical trials would likely resound with most patients considering participating in a study. The cultural element was most apparent in participants' suggestions for how to provide education and recruit Chinese, Korean and Vietnamese communities. The information that participants requested is mostly covered by standard consent processes. However, participants in this study also wanted information on who conducts the research, the past effectiveness of the drugs and how the drug works. The suggestions for promoting clinical trials are a good list for cultural tailoring for many ethnic groups.

The offer of hope that could be offered by clinical trials for those at the end stage of disease was a salient theme across focus groups. Luque et al[21] describes patients' expectations of hope as exchanges where participation in RCTs is contingent upon the expectation of receiving a therapeutic benefit. Clinical trials researchers refrain from the idea of offering hope because consent processes require a conservative approach to stating benefits. However, patients in this study were more concerned that they be given an assurance that if health benefits are found, they will be offered those benefits. Cases like the Tuskegee clinical trials should remind researchers that such options are not guaranteed. Given the high cost of therapies that have become available in the lifetimes of current patients like medical interventions for HIV, researchers should take seriously patients' concerns about benefitting from research in which they contribute.

Doctors play a critical role both in introducing and discussing clinical trials with their patients and in making recommendations.[22] However, many physicians do not talk to participants about clinical trials and they perceive many barriers to talking to patients, including lack of cultural knowledge and unease with discussing patient concerns.[23] Prior strategies to improve minority participation in clinical trials has had mixed success. Direct mailing, the use of communications media like radio and incentives do not always improve recruitment.[6, 25, 26, 27, 32] Other studies have reported higher response rates for direct mail when combined with community contacts and workshops.[28] Advertising placed in Chinese specific media, [29] printed media like brochures, fact sheets and other short publications and web-based interventions has been effective in some Asian populations.[30,31]

Improved community outreach efforts include training community members to be presenters for educational presentations and workshops, increasing health screenings and adherence to health care.[26, 28, 33, 34] Community recruiters can explain clinical trials in the participant's “native” language, establish trust in health providers, and create a relationship between recruiters and participants that enhances retention and enhances adherence to protocols.[24,33,35] Partnering with culturally appropriate, community-based partners for health interventions has advantages.[24, 29, 36] Community leaders can identify low cost but culturally meaningful incentives and identify holidays and other community events that could facilitate or restrict recruitment opportunities.[26, 29]

Limitations

The present study was meant to provide a range of participant beliefs and expectations and had several limitations. This convenience sample had a large percentage of study participants who were well connected to medical services, which may overestimate the community's knowledge of and interest in clinical trials. This may be partly due to the older age range of the sample. Expanding the study to capture younger participants, those with fewer years living in the US, and those not connected to a health care system would enhance the generalizability of these results.

Although a wide range of participant education levels was represented in the sample, only about 25% had less than a high school degree, which is unusual for participants of this age group. Populations with less than a high school degree may need educational materials in both English and their native language, materials that include graphics, and materials to match different literacy levels. A quantitative community survey is needed to confirm the present results and improve sample representativeness. Because the present study represented a community perspective, participants did not mention a number of strategies identified in other studies to promote minority recruitment to clinical trials.[6, 13, 25, 26, 34]

Conclusion

Improving access to clinical trials and recruiting sufficient numbers of this diverse community is an important five-year goal to achieve Healthy People 2020 objectives and diminish Asian American health disparities.[37] Public health agencies should work with researchers to strategically improve clinical trial referral networks in order to bolster the number and diversity of Asian American participants in clinical trials. Clinical trial sites located in areas with large numbers of Asian Americans should over-recruit to reach sample sizes that would allow for analysis by race. Increasing use of Community Based Participatory Research models in geographic areas with concentrations of Asian American populations, partnering with Asian American community based organizations, and including Asian American in health planning and policy meetings are important strategies to improve clinical trial recruitment.[38]

Clinical trials researchers also can improve Asian American recruitment by providing cultural sensitivity training to clinical recruitment staff including physicians. Clinical trials research needs to take advantage of new communication technologies and access social networks to provide flexible health education in native languages of the target population. Health information for Asian Americans is critically needed including better health education interventions, collection of epidemiological and lifestyle data and outcome evaluation from clinical trials with experience recruiting Asian Americans.[2] Asian American community members have narrow views of clinical trials with many thinking that trials only address end-stage disease, situations where there are no other treatment options and always include placebos. Concepts such as Ying/Yang, hot and cold balance may be more applicable to clinical trials dealing with lifestyle issues such as smoking, obesity, physical fitness or diet interventions. Stigmas about clinical trials include feeling like “guinea pigs,” concerns over consent processes and trust. These community issues can be addressed by proactive, positive messaging.

Innovations in health care depend on clinical trials to identify effectiveness and important side effects in minority populations.[12] Public health initiatives documented dramatic improvements in health screening rates and adherence to treatment regimens reducing health disparities, yet Asian American populations have not seen such success.[19, 20] This study suggests that strategic outreach to Asian American communities could make gains in improving knowledge about and interest in clinical trials. Low levels of clinical trial participation and knowledge gaps [10-12] make efforts to better recruit Asian critically important.

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References

1. Hoeffel, EM.; Rastogi, S.; Kim, MO., et al. The Asian population: 2010. Washington, DC: US Census Bureau; 2012. Available from: http://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf [cited 2013 Sep 23]
2. Wong, C.; Hosotani, H.; Her, J. [cited 2013 Aug 8] Information on small populations with significant health disparities: A report on data collected on the health of Asian Americans in Massachusetts. 2012. Available from http://www.iaas.umb.edu/publications/general/AA%20Health%20Data.pdf
3. American Cancer Society. [cited 2013 Aug 8] American Cancer Society: Cancer Facts & Figures 2012. 2012. Available from http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-031941.pdf
4. Kim W, Keefe RH. Barriers to healthcare among Asian Americans. Soc Work in Public Health. 2010; 25(3-4):286–295. [PubMed: 20446176]
5. Homji RM, Lakhoo S, Ray JG. Recruitment of immigrant and ethnic minorities in primary prevention trials of cardiovascular disease. QJM. 2011; 104(6):469–476. [PubMed: 21398665]
6. Mendoza DB, Williams MT, Chapman LK, et al. Minority inclusion in randomized clinical trials of panic disorder. J Anxiety Disord. 2012; 26(5):574–582. [PubMed: 22445317]
7. Williams M, Powers M, Yun YG, et al. Minority participation in randomized controlled trials for obsessive–compulsive disorder. J Anxiety Disord. 2010; 24(2):171–177. [PubMed: 20143498]
8. Las Nueces D, Hacker K, DiGirolamo A, et al. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. Health Serv Res. 2012; 47(3pt2):1363–1386. [PubMed: 22353031]
9. Pinsky PF, Ford M, Gamito E, et al. Enrollment of racial and ethnic minorities in the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial. J Natl Med Assoc. 2008; 100(3):291–298. [PubMed: 18390022]
10. Brown M, Moyer A. Predictors of awareness of clinical trials and feelings about the use of medical information for research in a nationally representative US sample. Ethn Health. 2010; 15(3):223–236. [PubMed: 20336563]
11. Ma GX, Fleisher L. Awareness of cancer information among Asian Americans. J Community Health. 2003; 28(2):115–130. [PubMed: 12705313]

12. Tu SP, Chen H, Chen A, et al. Clinical trials: Understanding and perceptions of female Chinese-American cancer patients. Cancer. 2005; 104(S12):2999–3005. [PubMed: 16247796]
13. Paterniti DA, Chen MS, Chiechi C, et al. Asian Americans and cancer clinical trials: A mixed-methods approach to understanding awareness and experience. Cancer. 2005; 104(S12):3015–3024. [PubMed: 16247795]
14. Gao, WZ.; Ma, GX. A Culturally Appropriate Education on Biospecimen Research Participation Among Chinese Americans: A Pilot Study. CNPC Program Meeting; 2012; NIH, Bethesda, MD.
15. Ma, GX.; Seals, BF.; Tan, Y., et al. Addressing Barriers to Asian American Participation in Biospecimen Research. CNPC Program Meeting; 2012; NIH, Bethesda, MD.
16. Tan, Y.; Seals, BF.; Ma, GX., et al. Increasing Asian American participation in clinical trials by addressing community concerns. CNPC Program Meeting; 2012; NIH, Bethesda, MD.
17. Lee, S.; Chen, L.; Jung, M., et al. Acculturation and cancer screening among Asian Americans: Role of health insurance and having a regular physician. CNPC Program Meeting; 2012; NIH, Bethesda, MD.
18. Pope C, Mays N. Qualitative Research in Health Care. MaldenWiley-Blackwell2006 Add: Patton, Michael Q. Qualitative Research & Evaluation Methods. Thousand OaksSage2002
19. Wang X, Fang C, Tan Y, et al. Evidence-Based intervention to reduce access barriers to cervical cancer screening among underserved Chinese American women. J Womens Health. 2010; 19(3): 463–469.
20. Ma GX, Shive S, Tan Y, et al. Community-based colorectal cancer intervention in underserved Korean Americans. Cancer Epidemiol. 2009; 33(5):381–386. [PubMed: 19914880]
21. Luque JS, Quinn GP, Montel-Ishino FA, et al. Formative research on perceptions of biobanking: what community members think. J Cancer Educ. 2012; 27(1):91–99. [PubMed: 21927867]
22. Lee SJ, Park LC, Lee J, et al. Unique perception of clinical trials by Korean cancer patients. BMC Cancer. 2012; 12(1):594. [PubMed: 23234342]
23. Nguyen TT, Somkin CP, Ma Y. Participation of Asian-American women in cancer chemoprevention research: Physician perspectives. Cancer. 2005; 104(12 Suppl):3006–3014. [PubMed: 16247807]
24. Gallagher-Thompson D, Rabinowitz Y, Tang PC, et al. Recruiting Chinese Americans for dementia caregiver intervention research: suggestions for success. Am J Geriatr Psychiatry. 2006; 14(8): 676–683. [PubMed: 16861372]
25. Rooney LK, Bhopal R, Halani L, et al. Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma. J Public Health. 2011; 33(4):604–615.
26. Gren L, Broski K, Childs J, et al. Recruitment methods employed in the prostate, lung, colorectal, and ovarian cancer screening trial. Clin Trials. 2009; 6(1):52–59. [PubMed: 19254935]
27. Brown SD, Lee K, Schoffman DE, et al. Minority recruitment into clinical trials: Experimental findings and practical implications. Contemp Clin Trials. 2012; 33(4):620–623. [PubMed: 22449836]
28. Keyzer JF, Melnikow J, Kuppermann M, et al. Recruitment strategies for minority participation: challenges and cost lessons from the POWER interview. Ethn Dis. 2005; 15(3):395–406. [PubMed: 16108298]
29. Wong CC, Tsoh JY, Tong EK, et al. The Chinese community smoking cessation project: A community sensitive intervention trial. J Community Health. 2008; 33(6):363–373. [PubMed: 18574679]
30. Love GD, Tanjasiri SP. Using entertainment-education to promote cervical cancer screening in Thai women. J Cancer Educ. 2012; 27(3):585–590. [PubMed: 22581487]
31. Markman M, Petersen J, Montgomery R. An examination of the influence of patient race and ethnicity on expressed interest in learning about cancer clinical trials. J Cancer Res Clin Oncol. 2008; 134(1):115–118. [PubMed: 17598129]
32. Breitkopf CR, Loza M, Vincent K, et al. Perceptions of reimbursement for clinical trial participation. J Empir Res Hum Res Ethics. 2011; 6(3):31–38.

33. Samsudeen BS, Douglas A, Bhopal RS. Challenges in recruiting South Asians into prevention trials: health professional and community recruiters' perceptions on the PODOSA trial. Public Health. 2011; 125(4):201–209. [PubMed: 21450322]
34. James RD, Yu JH, Henrikson NB, et al. Strategies and stakeholders: minority recruitment in cancer genetics research. Public Health Genomics. 2008; 11(4):241–249.
35. Wood CG, Wei SJ, Hampshire MK, et al. The influence of race on the attitudes of radiation oncology patients towards clinical trial enrollment. Am J Clin Oncol. 2006; 29(6):593–599. [PubMed: 17148997]
36. Ganz PA, Farmer MM, Belman M, et al. Improving colorectal cancer screening rates in a managed care health plan recruitment of provider organizations for a randomized effectiveness trial. Cancer Epidemiol Biomarkers Prev. 2003; 12(9):824–829. [PubMed: 14504190]
37. Healthy People 2020. [cited 2013 Aug 28] HealthyPeople gov U S Department of Health and Human Services. Available from http://www.healthypeople.gov/2020/default.aspx
38. Indian Health Service. [cited 2013 Aug 8] The Federal Health Program for American Indians and Alaska Natives. Available from http://www.ihs.gov/chr/

List of Abbreviations

RCT	randomized controlled trials
PLCO	prostate, lung, colorectal and ovarian
CBPR	community based participatory research

Table 1

Primary questions from moderator guide

1	What does anybody know about clinical trials?
2	What questions do you have about clinical trials?
3	If you decide to join the clinical trial, what are the reasons you would want to join?
4	What kinds of barriers make you not want to participate in clinical trials?
5	What do you want to know about clinical trials to participate?
6	Will having incentives affect your decision to participate in a clinical trial?
7	How does your family affect your decision to be in a clinical trial?
8	Will religious beliefs affect your decision to be in a clinical trial?
9	What cultural beliefs affect your decision to be in a clinical trial?
10	What would you suggest to promote clinical trial concepts to [ethnic group] community? How would you like to receive health information? What is best way to educate [ethnic group]?

Table 2

Participant Characteristics

Variables	**% (N)**
Gender [*] **(n=99)**	
Male	40 (40)
Female	60 (59)
Born in the US [*] **(n=92)**	
No	96 (88)
Yes	4 (4)
Ethnic Background (n=103)	
Chinese	53 (55)
Vietnamese	29 (30)
Korean	18 (18)
Age [*] **(n=102)**	Mean=64 (SD=12.77)
Less than 50	13 (13)
50-64	26 (26)
65-70	25 (25)
71 and above	37 (38)
Marital Status (n=103)	
Married	74 (76)
Never Married	6 (6)
Divorced/Separated	7 (7)
Widower	14 (14)
Education [*] **(n=101)**	
No Education/Elementary School	12 (12)
Below High School	15 (15)
High School Graduate	35 (35)
Some College/Bachelor's Degree	32 (32)
Graduate School or Above	7 (7)
Current Employment Status [*] **(n=97)**	
Employed	24 (23)
Unemployed	5 (5)
Retired	46 (45)
Homemaker	25 (24)
English Fluency [*] **(n=99)**	
Not at All	23 (23)
Not Well	45 (45)
Well/Very Well	31 (31)
Years in the US (n=103)	Mean=22 (SD=10.72)

Variables	**% (N)**
16 years and below	31 (32)
17 to 26 years	33 (34)
27 years and above	34 (37)
Knowledge about Clinical Trials [*] (n=94)	
None	62 (58)
Know a Little/Heard About It	26 (24)
Know Some	12 (11)
Know Well	1 (1)
Have Health Insurance [*] (n=101)	
No	15 (15)
Yes	85 (86)
Regular Physician Visit [*] (n=95)	
No	11 (10)
Yes	90 (85)

[*] Note: Cells do not sum to 103 due to missing data.

Table 3

Bivariate analysis of knowledge about clinical trials

Variables	Percent reporting they knew a little or more about clinical trials % (N)	Percent reporting no knowledge about clinical trials % (N)
Gender	N=93	
Male	49 (19)	51 (20)
Female	39 (21)	61 (33)
Born in the US	N=88	
No	45 (38)	55 (46)
Yes	25 (1)	75 (3)
Ethnic Background	N=97 ***	
Chinese	46 (24)	54 (28)
Vietnamese	15 (4)	85(23)
Korean	67(12)	33 (6)
Age	N=96	
Less than 50	62 (8)	39 (5)
50-64	35 (9)	65 (17)
65-70	48 (11)	52 (12)
71 and above	35 (12)	65 (22)
Marital Status	N=97	
Married	44 (32)	
Never Married/divorced/widowed	34(8)	
Education	N=95 ***	
Below High School	13 (3)	88 (21)
High School Graduate	35 (12)	65 (22)
Some College/Bachelor's Degree	68 (25)	32 (12)
Current Employment Status	N=92 ***	
Employed	70 (16)	30 (16)
Unemployed	33 (23)	67 (46)
English Fluency	N=95 **	
Not at All	20(4)	80 (16)
Not Well	39 (17)	61 (27)
Well/Very Well	61 (19)	39 (11)
Years in the US	N=97	
16 years and below	52 (16)	48 (15)
17 to 26 years	39 (12)	61 (19)
27 years and above	34 (12)	66 (23)
Have Health Insurance	N=96 *	
No	64 (9)	36 (5)

Variables	**Percent reporting they knew a little or more about clinical trials % (N)**	**Percent reporting no knowledge about clinical trials % (N)**
Yes	37 (30)	63 (52)
Regular Physician Visit	N=90	
No	56 (5)	44 (4)
Yes	42 (34)	58 (47)

[*] p<=.05;

[**] p<=.01;

[***] p<=.00

Table 4

Identified focus group themes and example quotes.

Motivations to Participate in Clinical Trials
Hope that participation in the clinical trials will provide options: “… [if] there is a small piece of hope that you can get better, then you should do it.”
Future family benefits. “I guess family must be the strongest motivation [to participate in clinical trials].”
Being sick enough that participants will try options not previously considered. “If I do not have a disease, I do not want to do it [be in a clinical trial].”
The absence of health risks. “If there is no risk to my life, I am willing to participate.”
Recommendation from a doctor/health care provider. “I will ask the doctor, and rely on doctor's guidance.”
Making a contribution to future. “To make the next generation better than our lives, we are better to be taking that new medicine and testing it.”
Perception that younger participants may be more knowledgeable about and interested in clinical trials.
Barriers to participation in clinical trials
Perception that placebos are the only option for clinical trials. “… If I am given a placebo, that means I am wasting my time for the treatment.”
Lack of trust in health care professionals: “Although the doctor says it is no problem, I am still worried and afraid …”
Mixed Opinions
All participants said “no” to the question of religion or culture having an influence. Later discussions included “others” that had beliefs that would be both for and against clinical trials.
Some participants thought incentives would be beneficial and others thought unnecessary.
What Participants Want to Know about Clinical Trials:
If the [drug] trial has been successfully tested on animals
Side effects of the drug
Success rates of the drug
How the drug works
The type of research that has already been completed
The organization that conducted the research
How long they can expect to live after the medication
How much it would cost to participate
How to Promote Clinical Trials
“Word of mouth” with a good reputation for the group conducting the clinical trial.
Partnering with community representatives to conduct outreach to subpopulations.
Common communication channels like brochures, flyers, radio, TV and newspapers.
Health educators talking to small groups, public discussion forums or workshops.
Having outreach tables or booths at community events or integrated into health fairs and other community activities.