Published in final edited form as:
*Cancer*. 2005 December 15; 104(12 Suppl): 2999–3005.

# Clinical Trials: Understanding and Perceptions of Female Chinese-American Cancer Patients

**Shin-Ping Tu, M.D., M.P.H.**[1], **Hueifang Chen, B.S.N., M.S., Ph.D.**[1], **Anthony Chen, M.D.**[2,3], **Jeanette Lim, R.N., M.P.H.**[4], **Suepattra May, M.P.H.**[5], and **Charles Drescher, M.D.**[6]

1 *Department of Medicine, University of Washington, Seattle, Washington.*

2 *International Community Health Services, Seattle, Washington.*

3 *Department of Family Medicine, University of Washington, Seattle, Washington.*

4 *Program for Appropriate Technology in Health, Seattle, Washington.*

5 *Department of Anthropology, History and Social Medicine, School of Medicine, University of California–San Francisco, San Francisco, California.*

6 *Division of Public Health Sciences, Fred Hutchinson Cancer Research Center, Seattle, Washington.*

## Abstract

Under-representation of minority and female participants prompted the U.S. legislature to mandate the inclusion of women and minorities in federally funded research. Recruitment of minorities to participate in clinical trials continues to be challenging. Although Asian Americans constitute one of the major minority groups in the U.S., published literature contains sparse data concerning the participation of Asian Americans in cancer clinical trials. The authors completed qualitative, semistructured interviews with 34 participants: Chinese-American female cancer patients ages 20–85 years or their family members. Interviews were conducted in Cantonese, Mandarin, or English and were audiotaped. Chinese interviews were translated into English, and all interviews were transcribed subsequently into English. A team of five coders individually reviewed then met to discuss the English transcripts. The authors used the constant comparative technique throughout the entire coding process as part of the analysis. Among participants, 62% lacked any knowledge of clinical trials, and many expressed negative attitudes toward clinical trials. Barriers to participation included inadequate resources, language issues, and a lack of financial and social support. Facilitating factors included recommendations by a trusted oncologist or another trusted individual and information in the appropriate language. It is noteworthy that family members played an important role in the cancer experience of these participants. To promote participation, there is a need to increase knowledge of clinical trials among Chinese cancer patients. It also is necessary to examine the applicability of current patient-physician communication and interaction models. In addition, decision-making based on Asian philosophies within the context of Euro-American bio-ethics requires further study.

Address for reprints: Shin-Ping Tu, M.D., M.P.H., Division of General Internal Medicine, Harborview Medical Center, Box 359780, 325 Ninth Avenue, Seattle, WA 98104; Fax: (206) 744-9917; E-mail: shinping@u.washington.edu.

Presented at Asian American Network for Cancer Awareness, Research, and Training (AANCART): Fifth Asian American Cancer Control Academy, Sacramento, California, October 22–23, 2004.

Supported by grant P50 CA83636-03 from the National Cancer Institute.

The authors thank the study participants for taking the time to participate in interviews and for sharing their insightful experiences. This work would not have been possible without the dedication of the translator (Kathy Lin) and the transcriptionists (Mary Walsh, Kendra Eberle, and Donna Keller). The authors also greatly appreciate the assistance of Kristin Bacon with article preparation.

**Keywords**

traditional Chinese medicine; patient participation; Asian Americans; clinical trials

Adequate representation of women and minorities in cancer clinical trials is crucial, because, for many diseases, biologic, epidemiologic, prognostic, and outcome variables differ by gender and/or racial group. The applicability of treatment results depends, in part, on whether the study sample represents the entire spectrum of patients who have the type of cancer.[1] Under-representation of minority and female participants prompted the U.S. legislature to mandate the inclusion of women and minorities in federally funded research.[2–8] In 1994, to address this disparity, the National Institutes of Health introduced guidelines for the inclusion of women and minorities.[9]

The recruitment of minorities into clinical trials, however, has proven to be challenging.[2–4,7,10–12] Sociocultural factors that impede clinical trials participation include lack of access to healthcare, language barriers, inadequate number of minority healthcare professionals, racial discrimination and segregation, and cultural beliefs and myths regarding specific diseases and illness. An inability to accommodate cultural and economic diversity also limits potential participation by minorities. The complexities of consent forms and procedures prevent the participation of many populations for various reasons, such as low literacy levels and inadequate explanation of trial benefits. Among African Americans, the Tuskegee Study resulted in a legacy of distrust in both research and the medical community.[13,14]

For economically disadvantaged populations, costs of tests, treatments, and lost wages also must be taken into consideration.[7] Furthermore, whereas academic medical research centers usually have adequate infrastructure to conduct clinical trials, many community-based studies do not have the same support.[15]

Asian Americans constitute one of the major minority groups in the U.S. The Asian-American population increased dramatically from just over 1 million in 1970 to > 10 million in 2000.[16–18] Asians and Pacific Islanders will continue to be the fastest growing ethnic groups in the U.S. and it is projected that, by 2050, Asians and Pacific Islanders will reach 41 million (10.3% of the U.S. population).[19]

Despite this growth, the published literature contains sparse data concerning the recruitment or participation of Asian Americans into cancer clinical trials. One group reported that Asian Americans are more likely to participate in screening/diagnostic trials than in treatment trials (4.6% vs. 2.0%, respectively).[5] Older Asian Americans (age 65 yrs or older) also had lower participation. Those authors noted that their study assessed only the numerical aspect of the clinical trial accrual process and that other factors influencing participation, such as knowledge, attitudes, and the effects of culture, have not been examined.

The 2000 Census identified 2.4 million ethnic Chinese living in the U.S., representing the largest Asian-American ethnic group. Nearly 70% of Chinese Americans are foreign born, and Chinese is now the second most prevalent foreign language spoken at home.[20]

In this report, we present findings from a qualitative study of Chinese female cancer patients and family members. Through in-depth, semistructured interviews, we examined participants' understanding and perceptions of clinical trials. These interviews also explored barriers and facilitators to clinical trial participation.

## MATERIALS AND METHODS

Chinese American women (ages 20–85 yrs) with cancer who were treated in the U.S. were eligible for the study. Family members of eligible Chinese-American women with cancer also were interviewed for the study.

Several sources referred potential participants to the study: 1) family physicians at a local community clinic serving Asian Americans, 2) community coalition members, 3) research staff, and 4) study participants (snowball sampling). The Fred Hutchinson Cancer Research Center Institutional Review Board approved all study procedures.

### Data Collection

Between April 2001 and November 2002, a bilingual (English and Mandarin), bicultural ethnographer conducted semistructured, in-depth interviews with 34 participants. In total, 37 interviews were completed; 3 participants were interviewed twice to clarify information and explore emerging issues. Of the interviews, 27 were conducted directly in Mandarin, 8 were conducted in Cantonese through an interpreter, and 2 were conducted in English.

Each interview lasted from 45 minutes to 1 hour and was audiotaped. Interviews conducted in English were transcribed verbatim, whereas Chinese interviews were translated and interpreted into English and then transcribed verbatim for coding.

### Data Analysis

We analyzed transcripts using open coding, axial coding, and constant comparative methods.[21] First, line-by-line coding identified descriptive categories (opening coding). Comparison of all categories resulted in higher level conceptual categories that identified correlations between the categories (axial coding). We used the constant comparative technique throughout the entire coding process to distinguish categories and phenomena.

Our team of five coders represented disciplines from clinical medicine, public health research, and cross-cultural care. In addition to the varied perspectives, members also had different levels of bilingual fluency (English and Mandarin) and acculturation.

Each member individually reviewed and coded every transcript before the coding meetings. During these meetings, we explored the meaning of the data, identified categories and their correlations, clarified discrepancies of interpretations, and developed questions to clarify any ambiguous or incomplete information for subsequent interviews. Synthesized coding for each transcript was then entered into the QSR NUD*IST computer program (QSR International Pty Ltd., Doncaster, Victoria, Australia) for further analysis.

To establish validity, we performed member checking by bringing the data, analytic categories, interpretation, and conclusions back to members of the groups from whom the data originally were collected.[22] Four focus groups, comprised of 15 Chinese-American female cancer patients, confirmed the findings, clarified emerging issues from the coding process, and explored other aspects of the cancer experience.

## RESULTS

### Participant Characteristics

Of the 34 participants, 29 were female cancer patients and 5 were family members (1 mother, 1 husband, 2 daughters, and 1 son). Participant characteristics are detailed in Table 1. Only 26% of the participants reported fluency in English. Most participants were born in mainland China, were fluent in Mandarin, and currently were married. Our sample was educated, with

the majority residing in the U.S. for more than 10 years, and most had some form of health insurance.

Among seven participants who recalled being recruited to participate in clinical trials, only one participated: two were ineligible, and four refused. Three women, who were recruited to participate in nonclinical research, all participated.

## Knowledge of Clinical Trials

Knowledge of clinical trials was broached with 33 participants. Among them, seven participants had never heard of clinical trials (in neither Chinese nor English terms) (Table 2). Of those who had heard of clinical trials, the role of clinical trials in cancer treatment was understood poorly. In fact, 62% lacked any knowledge of clinical trials upon further questioning. One interviewee thought:

> Seems like [they] interview some individuals to see [what] their experience [is], just like you interview me right now. I think it's like that, isn't it?

Another understood it this way:

> Clinical trial, it is to take this case to study. Take this person's medical history or condition and do a study.

The complexities of clinical trials proved to be confusing. One participant shared her friend's experience when an option to participate in a clinical trial was offered after a course of standard treatment. The participant thought that, if the clinical trial was necessary, then this option should have been offered at the beginning of treatment.

The concept of randomization also proved challenging for participants. Although only three participants stated that they had never heard of the term randomization, their difficulty with this concept is exemplified below.

> Subject: *I'm not familiar with the English [term of randomization]. What is that in Chinese?*
>
> Interviewer: *That word in Chinese means… it means that, even though it is a "clinical trial," not everybody will receive it. Not everyone will receive the [research] treatment method that was suggested. Half of the patients will receive treatment, half of them won't. But who is going to—to receive it or not to receive it, they have to, um, use— they have to draw straws to decide. I don't know whether you're familiar with this or not.*
>
> Subject: *What do you mean, how [do] they decide?*
>
> Interviewer: *They have to follow… maybe they will design [it] a different way, but basically [to randomize] is—for example—the first patient comes in, maybe he will receive the treatment, and the second patient that comes in, he— he will not receive the treatment. And then the next patient comes in, then she will receive the treatment, and then the next patient comes in and there's no treatment. Something like this.*
>
> Subject: *So, this is decided by the doctors? Or is it [the] patients, [who] arrange it?*

## Attitudes toward Clinical Trials

Seventeen interviews involved more extensive exploration of participants' attitudes toward clinical trials. All except one participant expressed negative perceptions of clinical trials. The majority (65%) of these participants associated clinical trials as the last resort.

> When you have a disease that is very serious, you would go to that program. A dying horse could be used as a guinea pig to be treated.… I felt when other methods have failed, then you go to the clinical trials.

In fact, one participant believed that, if a physician started to discuss clinical trials with her, then it would imply that she no longer had any hope.

> So, my feeling is that, when doctors mention a clinical trial, it seems like [they are] going to give up on you.

Furthermore, participants often believed that new treatments used in clinical trials would pose unknown suffering to the patient. In response to a hypothetical scenario, when only clinical trials are available,

> If I have no way to save [treat] it, then I won't even do it [clinical trial].… Because I don't want to continue to suffer any more. I don't want to be like mice, to be tested on.

### Barriers to Clinical Trials Participation: Uncertainties and Risks

The interviews elicited barriers to clinical trials participation from 20 participants (Table 3). Among these participants, four had been recruited to participate in clinical trials. Interview participants expressed distrust of medications and treatments still in the development phase. Concerns about the uncertainties and risks (i.e., treatment effectiveness and side effects) were main reasons cited for refusing to participate.

In reference to a college student's death from participating in a research study:

> If she knew this was going to be risky for her life, then she should not have participated in it.… For example, the reason I participated in your study [is] because I think it will contribute some benefits to this community and nursing care. That's why I came. But if there's anything that might be dangerous or threaten lives, then I won't participate [in] it.

Another participant explained why she would use standard treatment first:

> Because, with this one [treatment], the doctor says that, if all goes well, the percent [of cure] is 99%. But if you use the new medicine, maybe there would be other side effects, then maybe you don't have any hope.

Participants stated that they would not choose (for themselves or their family members) treatments that had not been proven effective.

> The patient's life is in their [doctors'] hands. So, for today's case, then you can do it on some other patient. Don't do it on my parent, because that's how everybody thinks. Otherwise, who will take care of their parents and take care of their kids? Right? Please don't take my Mom or Dad for a joke [guinea pig].

Additional barriers included lack of resources. There is insufficient clinical trials information, there are language barriers, and there is a lack of financial and social support. One participant who worked extensively with new Chinese immigrants offered her insights on cultural barriers:

> Like those [who] just came from China, those who just immigrated, they may not want to [participate in clinical trials]. Because they still don't know what you are going to do.… They are not easily persuaded.… Why they are like this? Is this doctor capable or not? Suspicious!… Don't know whether or not the translation is enough. Is there anything missing?… I think it would be very difficult [for Chinese people to agree to participate in clinical trials because] they don't know what you are doing.

> Anything that is not their business, they won't pay attention [to].… It's more difficult, especially with Chinese people, because we don't have this custom [to] volunteer!

## Facilitators to Clinical Trial Participation

Twenty-five participants discussed factors that facilitated clinical trial participation for Chinese Americans (Table 3). The most frequently cited factor was the absence of other available treatments. Recommendation by a trusted oncologist or another trusted individual also was important.

> If he [the oncologist] said it's needed then I will [do it].… There must be reasons for them wanting me to participate. … If the doctor asked me to go [for the treatment being researched], I would go.

> Yes I would [participate in clinical trials]. Actually it really should be up to the doctor. If the doctor gives you confidence, I think you would participate.

> I will listen to the doctor, because I don't understand – really I don't understand. I will listen to the doctor. If he wants me to try the new [medicine], I will try [it].

Focus group data confirmed the importance of trust in recruiting Chinese-American women into clinical trials. Women in the focus groups agreed that the physician who conducts the clinical trial should be the physician who is familiar with their prior cancer treatment experiences.

Eight participants were willing to participate in clinical trials if it would benefit other individuals or future generations. Research that is not harmful to the body also merits consideration:

> As long as there is nothing hurting you, then it's okay. You can try it… If it does not cause a big harm to the body, then it's okay.

Six participants indicated that more information would help them to make "intelligent" decisions. Other facilitators included no language barriers and no out-of-pocket costs.

## Cultural Factors

In these interviews, participants described their social framework with its associated roles and expectations. Key figures in the cancer experience are the oncologist, the family, and the patient. Expectations and lines of communication between the involved parties reflect cultural values that differ from the mainstream American culture.

A recurrent theme from the interviews was family involvement (24 participants), which played a major role in the decision regarding treatment. For instance, one participant agreed to a genetic study but not a trial study because of her family's concerns.

> They [the physicians] said they would do both. If I want to participate, then I have to do both (having injection and taking medicine). That's why I didn't want to do it… But he [the physician] said there is a risk that might increase the cancer cells. So when I told my brothers, my older brother and older sister, no one wanted to take this risk… Because they didn't want to take the risk. The people told us there is a chance that it might increase the cancer cells, because they are still doing the study right now. Plus, I already felt pretty miserable, so I didn't want to do anything else anymore.

Finally, the frequent references to traditional Chinese health beliefs and practices in the interviews highlight the significance of this unique cultural heritage to Chinese cancer patients. These beliefs and practices played an integral role in the cancer experience of 23 patients, many

of whom used Chinese herbal medicines or traditional food remedies during or after western treatments.

> When Dr. C. did the surgery, he asked me if I was taking any Chinese medicines, and I said yes, I was. At that time, I started taking it [Chinese medicines], but I did not do any acupuncture. I just got some medicines from a Chinatown herbal store. Those medicines maintain my body's energy and strengthen my body's constitution. Also, at that time, my stomach and intestines did not feel that good, so I asked them [herbalists at the Chinese herbal store] to give me some medicine for that. So, hopefully, when I got chemotherapy, I can eat better and absorb [the food] better, in order to have the strength to do the chemo. So, I was using the Chinese medicines to nourish my stomach and my intestines.

> I would just cook some soup to neutralize it [effects from chemotherapy]. Uh, for example, like the American "gin seng" soup. If I felt I'm really hot [Chinese concept of internal heat], I would drink that kind of stuff [soup]. Or sometimes I would cook some soup, like, winter melon soup, bean soup; they are all pretty helpful too. Yeah, I would cook a "qing" soup [to relieve the Chinese concept of internal heat]. After I drank that soup, I felt much better, because [my] inside felt like fire. After I drank the soup, it seemed to calm it [feeling like fire] down.

## DISCUSSION

Although this study revealed many barriers to clinical trials recruitment that are common to the general patient population and to other minority groups,[23] several unique features were elicited. The results suggest that, as a first step toward clinical trials recruitment, there is an urgent need to increase knowledge of clinical trials among Chinese cancer patients. Despite the negative attitudes and numerous barriers to clinical trial participation, we found that unique issues applicable to Chinese cancer patients can facilitate recruitment and participation. In contrast to the fear and distrust of African Americans toward the health-care system and healthcare professionals,[7,13,14] participants in the current study reported their trust and acceptance of their physicians' recommendations.

The physician discussed in these interviews was the oncologist rather than the primary care physician, as expected. Because the interaction of a cancer patient is overwhelmingly with the oncologist during the treatment period, the emphasis on the oncologists' expertise was prominent in our interviews. Recommendation by the physician overshadowed the few discussions on other recruitment strategies. It is noteworthy that the ethnicity of the physician was not identified as a major factor for clinical trial participation in these interviews; however, language was an issue.

Sixteen participants described language barriers in their medical care, ranging from communicating with physicians, to understanding English documents, and using information services. Although these discussions regarding language issues did not refer specifically to clinical trials, the implications of this barrier to medical care and participation in clinical trials are evident. Also noteworthy was the expectation that the "physicians" conducting trials should be physicians familiar with their prior cancer treatment experiences. Such expectations of research and clinical roles are not congruent with the complex structure of medical research that is comprised of multidisciplinary teams and often involves multiple sites.

Family involvement also appears to play a larger role than that identified previously. This is consistent with cultural traditions and social roles of Chinese women and contrasts with a study of African-American, women who did not rely on other individuals for help with their decisions.[24] It remains to be clarified whether family involvement also applies to male Chinese

patients. It is noteworthy that the discussions of family and their influence are not concordant with American norms of individual patient autonomy and decision-making.[25–27] The ramifications of such discordance between Chinese cancer patients and the American philosophical and bioethical frameworks may be profound and merit further research.

The strengths of this study include the qualitative methodology. These in-person interviews provided rich data that are unencumbered by ethnocentric biases.[28,29] However, as an exploratory study, our qualitative findings require verification with larger surveys that include men and women with different levels of acculturation and socioeconomic backgrounds. It also would be interesting to explore the relevance of these findings among other Asian-American ethnic groups. Nonparticipation in this study merits some discussion because of the sensitivity of the interview topic. One potential participant who refused to be interviewed cited concerns of eviction if her landlord discovered she had cancer. We surmise there were other eligible participants who considered the discussion of cancer either taboo, culturally inappropriate, or too risky and, thus, refused to be referred for the study.

In 2000, the Association of Asian Pacific Community Health Organizations (AAPCHO) published its needs assessment for the *Capacity-Building Initiative for Asian Americans and Pacific Islanders to Participate in Clinical Research Studies*.[30] That report, which was based on focus groups and data from key informants, highlighted the diversity of the Asian-American/Pacific Islander population. That report also examined the importance of language and ethnic congruence among patients, providers, and researchers. The barriers to clinical trials participation that were identified included: 1) lack of understanding of clinical research; 2) lack of understanding regarding how clinical research is conducted; 3) lack of awareness regarding the individual and global benefits of clinical research; 4) negative perceptions about clinical research, including fears of being treated as “guinea pigs”; 5) fears of what researchers would do with the research data; 6) stigmatization of cancer; and 7) lack of time. Facilitators to research included: 1) community collaboration, 2) cultural competency, 3) involvement of individuals who speak Asian languages in the research program to facilitate communication, 4) incorporation of community beliefs and practices into the program, and 5) appropriate acknowledgement and incentives for the community to participate.

Our findings corroborate AAPCHO’s needs assessment. According to our findings, the knowledge of clinical trials among the Chinese participants in this study was inadequate. Information in the appropriate language is needed urgently as a small step toward the complex path of their recruitment into clinical trials. Given the prominence of the physician and the family in these interviews, the applicability of current models of patient-physician communication and interaction to this minority group needs to be examined. In addition, decision-making based on Asian philosophies within the context of Euro-American bioethics also requires further study.

## References

1. Hutchins LF, Unger JM, Crowley JJ, Coltman CA Jr, Albain KS. Under-representation of patients 65 years of age or older in cancer-treatment trials. N Engl J Med 1999;341:2061–2067. [PubMed: 10615079]
2. Hodge FS, Weinmann S, Roubideaux Y. Recruitment of American Indians and Alaska Natives into clinical trials. Ann Epidemiol 2000;10:41–48.
3. Holcombe RF, Jacobson J, Li A, Moinpour CM. Inclusion of black Americans in oncology clinical trials. Am J Clin Oncol 1998;22:18–21. [PubMed: 10025373]
4. Brown DR, Fouad MN, Basen-Enguist K, Tortolero-Luna G. Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. Ann Epidemiol 2000;10:13–21.

5. Alexander GA, Chu KC, Ho RC. Representation of Asian Americans in clinical cancer trials. Ann Epidemiol 2000;10:S61–S67. [PubMed: 11189094]
6. Underwood SM. Minorities, women, and clinical cancer research: the charge, promise, and challenge. Ann Epidemiol 2000;10:S3–S12. [PubMed: 11189090]
7. Swanson GM, Ward AJ. Recruiting minorities into clinical trials: toward a participant-friendly system. J Natl Cancer Inst 1995;87:1747–1759. [PubMed: 7473831]
8. Mouton CP, Harris S, Rovi S, Solorzano P, Johnson MS. Barriers to black women's participation in cancer clinical trials. J Natl Med Assoc 1997;89:721–727. [PubMed: 9375475]
9. U.S. Department of Health and Human Services. NIH guidelines on the inclusion of women and minorities as subjects in clinical research. Fed Regist 1994;59:14508–14513.
10. Lovato LC, Hill K, Hertert S, Hunninghake DB, Probstfield JL. Recruitment for controlled clinical trials: literature summary and annotated bibliography. Control Clin Trials 1997;18:328–352. [PubMed: 9257072]
11. Green BL, Partridge EE, Fouad MN, Kohler C, Crayton EF, Alexander L. African-American attitudes regarding cancer clinical trials and research studies: results from focus group methodology. Ethn Dis 2000;10:76–86. [PubMed: 10764133]
12. Advani AS, Atkeson B, Brown CL, et al. Barriers to the participation of African-American patients with cancer in clinical trials: a pilot study. Cancer 2003;97:1499–1506. [PubMed: 12627515]
13. Shavers VL, Lynch CF, Burmeister LF. Knowledge of the Tuskegee study and its impact on the willingness to participate in medical research studies. J Natl Med Assoc 2000;92:563–572. [PubMed: 11202759]
14. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. Ann Epidemiol 2002;12:248–256. [PubMed: 11988413]
15. Kaluzny A, Brawley O, Garson-Angert D, et al. Assuring access to state-of-the-art care for U.S. minority populations: the first 2 years of the Minority-Based Community Clinical Oncology Program. J Natl Cancer Inst 1993;85:1945–1950. [PubMed: 8230286]
16. U.S. Department of Commerce. Statistical abstract of the United States. Washington, DC: U.S. Department of Commerce; 1995.
17. U.S. Census Bureau. Population estimates program. Washington, DC: U.S. Census Bureau; 2000.
18. Lin-Fu JS. Asian and Pacific Islanders: an overview of demographic characteristics and health care issues. Asian Am Pacific Isl J Health 1993;1:21–36.
19. U.S. Census Bureau. National population projections, vol 2004. Washington, DC: U.S. Census Bureau; 2001.
20. U.S. Census Bureau. 2000 Census of population and housing. Washington, DC: U.S. Department of Commerce Economics and Statistics Administration; 2000.
21. Strauss, AC. Basics of qualitative research: grounded theory procedures and techniques. Thousand Oaks, CA: Sage Publications; 1990.
22. Lincoln, YS.; Guba, EG. Naturalistic inquiry. Thousand Oaks, CA: Sage Publications; 1985.
23. Cox K, McGarry J. Why patients don't take part in cancer clinical trials: an overview of the literature. Eur J Cancer Care (Engl) 2003;12:114–122. [PubMed: 12787008]
24. Unson CG, Dunbar N, Curry L, Kenyon L, Prestwood K. The effects of knowledge, attitudes, and significant others on decisions to enroll in a clinical trial on osteoporosis: implications for recruitment of older African-American women. J Natl Med Assoc 2001;93:392–401. [PubMed: 11688920]
25. Dworkin, G. Autonomy and informed consent. In: Abram, MB.; Ballantine, HT.; Dunlop, GR., et al., editors. Making health care decisions, the ethical and legal implications of informed consent in the patient-practitioner relationship. The President's Commission for the study of ethical problems in medicine and biomedical and behavioral research. Washington, DC: U.S. Government Printing Office; 1982. p. 63-81.
26. Hahn, RA. Culture and informed consent: an anthropological perspective. In: Abram, MB.; Ballantine, HT.; Dunlop, GR., et al., editors. Making health care decisions, the ethical and legal implications of informed consent in the patient-practitioner relationship. The President's Commission for the study of ethical problems in medicine and biomedical and behavioral research. Washington, DC: U.S. Government Printing Office; 1982. p. 37-62.

27. Meisel A, Kuczewski M. Legal and ethical myths about informed consent. Arch Intern Med 1996;156:2521–2526. [PubMed: 8951294]

28. Eyton J, Neuwirth G. Cross-cultural validity: ethnocentrism in health studies with special reference to the Vietnamese. Soc Sci Med 1984;18:447–453. [PubMed: 6729523]

29. Pasick RJ, Stewart SL, Bird JA, D'Onofrio CN. Quality of data in multiethnic health surveys. Public Health Rep 2001;116(Suppl 1):223–243. [PubMed: 11889288]

30. Oakland: Association of Asian Pacific Islander Community Health Organizations; 2000. Association of Asian Pacific Islander Community Health Associations. Capacity building initiative for Asian Americans and Pacific Islanders to participate in clinical research studies: summary report of needs assessment

## TABLE 1

Participant Characteristics ($n$ = 34)

| Characteristic | No. of participants[a] | % |
|---|---|---|
| Female gender | 32 | 94.1 |
| Age | | |
| 30–39 yrs | 1 | 2.9 |
| 40–49 yrs | 16 | 47.1 |
| 50–59 yrs | 9 | 26.5 |
| 60–69 yrs | 5 | 14.7 |
| 70–79 yrs | 2 | 5.9 |
| 80–89 yrs | 1 | 2.9 |
| Mean age in yrs | 53.3 | |
| Median age in yrs | 50.0 | |
| Age range in yrs | 36–80 | |
| Place of birth | | |
| Mainland China | 16 | 47.1 |
| Taiwan | 11 | 32.4 |
| Hong Kong | 4 | 11.8 |
| Vietnam | 1 | 2.9 |
| Other | 2 | 5.9 |
| Languages/dialects spoken fluently | | |
| Cantonese | 19 | 55.9 |
| Mandarin | 24 | 70.6 |
| Vietnamese | 0 | 0.0 |
| English | 9 | 26.5 |
| Marital status | | |
| Currently married | 20 | 58.8 |
| Previously married | 11 | 32.4 |
| Never married | 2 | 5.9 |
| Religion | | |
| Buddhism | 7 | 20.6 |
| Christianity | 14 | 41.2 |
| None | 13 | 38.2 |
| Educational level | | |
| 0–7 yrs | 3 | 8.8 |
| 7–12 yrs | 9 | 26.5 |
| ≥13yrs | 22 | 64.7 |
| Mean and median in yrs | 13.9 | |
| Range in yrs | 3–20 | |
| Time in the U.S. | | |
| 0–4 yrs | 0 | 0.0 |
| 5–10 yrs | 6 | 17.6 |
| >10 yrs | 28 | 82.4 |
| Mean and median in yrs | 20.6 | |
| Range in yrs | 5–47 | |
| Type of housing | | |
| Subsidized | 3 | 8.8 |
| Rented | 4 | 11.8 |
| Owned | 27 | 79.4 |
| Health insurance | | |
| Yes | 32 | 94.1 |
| Medicaid | 6 | 17.6 |
| Medicare | 4 | 11.8 |
| Basic health plan (state subsidized) | 7 | 20.6 |
| Private insurance | 20 | 58.8 |

[a] Sample sizes may not total 34 due to missing values.

## TABLE 2

Knowledge and Attitudes Toward Clinical Trials

| Variable | No. of responses (%) |
|---|---|
| Knowledge of the term "clinical trials" (*n* = 33 respondents) | |
| Never heard of clinical trials | 7 (21) |
| Heard of clinical trials | 26 (79) |
| But lacked any knowledge | 16 (62) |
| And had some knowledge | 5 (19) |
| And had lots of knowledge | 4 (15) |
| But no data regarding the scope of understanding | 1 (4) |
| Attitudes toward clinical trials (*n* = 17 respondents) | |
| Used as a human guinea pig | 12 (71) |
| The last resort | 11 (65) |
| More suffering | 6 (35) |
| Prefer safer treatments | 2 (12) |

## TABLE 3

Barriers and Facilitators to Clinical Trial Participation

| Variable | No. of responses (%) |
|---|---|
| Barriers to clinical trials participation ($n$ = 20 respondents) | |
| Uncertainties of clinical trials (risks, effectiveness, side effects) | 11 (55) |
| Language barrier | 3 (15) |
| Insufficient information | 3 (15) |
| Lack of financial and other support | 2 (10) |
| Facilitators for clinical trials participation ($n$ = 25 respondents) | |
| No other effective treatments | 10 (40) |
| Recommended by trusted individual (including oncologist) | 9 (36) |
| Altruism | 8 (32) |
| More information | 6 (24) |
| Good treatment effectiveness | 3 (12) |
| Not harmful to the body | 3 (12) |