

Research Participation Among Asian American Women at Risk for Cervical Cancer: Exploratory Pilot of Barriers and Enhancers

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Abstract The purposes of this exploratory pilot were to describe perceived barriers to participation in cervical cancer prevention research, and identify culturally-appropriate communication strategies to recruit Asian women into cancer prevention research. This thematic analysis of transcripts, from focus groups and in-depth interviews, was conducted in English, Vietnamese, and Mandarin Chinese, at a community clinic in Philadelphia, Pennsylvania. Thirty participants were either Vietnamese (35%) or Chinese (65%). Mean age was 36.8 (SD 9.9 years). Reasons for non-participation were: lack of time, inconvenience, mistrust of institutions and negative experiences, lack of translated materials, feeling intimidated by English, and the lack of translation of key words or terms. Enhancers of

participation were: endorsement by a spouse, monetary compensation, and a personalized approach that offers a benefit for Asian women. To increase participation, first one must remove language barriers and, preferably, use specific dialects. Second, one must specify if benefits are indirectly or directly related to the family or cultural group. Asian research participants in our study consistently expressed that a significant motivator was their desire to be of help, in some way, to a family member or to the Asian community in general.

Keywords Asian women · Vietnamese · Chinese · Research participant · Recruitment strategies · Women's health research

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Background

Cervical cancer is the second most common malignant disease in women worldwide, and the leading cause of death in women in countries without screening programs [1–3]. Incidence rates vary between different countries. Per 100,000 women there are 20–29.9 cases in Vietnam; 10–19.9 case in Thailand and Laos; and 2–9.9 cases in the United States and China [4]. In the United States (US), disparities exist by race and ethnicity resulting in incidences per 100,000 as follows: Hispanic 14.7, African American 13.0, Asian American 9.3, White 8.6, and American Indian/Alaskan 7.2 [5]. The incidence for Vietnamese American women is particularly striking at 43.0 per 100,000, among the highest worldwide, and even higher than rates documented in Vietnam [6].

An Asian woman's lifetime risk of cervical cancer in the US is 1 in 138. About 3,670 women died from this disease in 2007 [5]. Nationally, an estimated 11,150 new cases of cervical cancer will be diagnosed each year. This figure does not include the many more women diagnosed with cervical dysplasia (pre-cancer) who will require colposcopy, biopsy, cryosurgery, or other treatment to prevent cancer progression. However, sixty-eight percent of Asian American women reported having the lowest rate of Pap testing (64%) compared to Whites (84%), African Americans (86%) and Latinas age 18 or older (78%) [7]. Failure to receive routine Pap tests can result in missed opportunities to treat cervical dysplasia before it becomes malignant. Women with low rates of Pap testing are the ones who would benefit most from HPV vaccination.

Asian Women Participation in Research

A major concern among researchers is the insufficient data on the health status of Asian women [8] as a result of low participation in clinical trials [9]. Des Jarlais et al. [10] reported that among 13,433 women recruited for a breast cancer prevention study, Asians women had the highest rate of refusal (55.4%) compared to Blacks (40.7%), Latinas (33.4%) and Whites (37.4%). Three reasons are documented for low enrollment rates: (1) the absence of translated study materials in their native language [11] and the associated high costs of translation, which may contribute to systematic exclusion from clinical trials; [12, 13] (2) passive exclusion associated with cultural stereotypes; [14] and (3) lack of confidence in physicians, and the feeling that physicians look down on them [15, 16].

Chinese and Vietnamese people constitute a large proportion of a growing population, both nationally and in the study area (Pennsylvania) [17]. Many of them are

low-income immigrants with limited English proficiency [18–21]. Consequently, there is a growing need to expand our understanding of this population. We need to identify the existing barriers to employing effective prevention strategies and identify specific ways to develop culturally appropriate strategies to recruit Asian women as research participants.

Asian American women are disproportionately affected by cervical cancer, and this group has been underrepresented in clinical research [22–24]. A targeted approach is needed to adequately recruit Asian American women into comprehensive studies of the multiple factors that contribute to their risk for cervical cancer. There are some data on Asian-American women and the behavioral factors associated with medical procedures such as Pap testing. We need more information on behavioral issues related to participation in HPV and HPV vaccine uptake trials, treatment protocols, and studies related to cancer risk.

Methods

This descriptive pilot explores perceived barriers and facilitators to participation in prevention research that focuses on cervical cancer. We examine ways to develop effective, culturally-appropriate communication strategies to recruit Chinese- and Vietnamese- American women into cervical cancer prevention studies that include biosampling. The methodology follows the recommendations of Johnstone et al. [25] and Culley et al. [26] to use focus groups to identify barriers and provide a gateway to participation in research. We used thematic content analysis of narrative data to answer the specific research questions: what are the barriers to participation in research among Asian American women at-risk for cervical cancer; and what specific recruitment strategies could enhance study enrollment?

Participants

The study targeted Chinese-American or Vietnamese-American women between the ages of 21 and 65 years. Women were eligible if they spoke English, Mandarin, or Vietnamese. A woman was not eligible if she had a personal history of cervical cancer or hysterectomy (no cervix). Approval for human subject research was obtained from the Institutional Review Board of the University of Pennsylvania (UPENN), the Abramson Cancer Center of UPENN, and the Philadelphia Department of Public Health (PDPH). Written consent forms were prepared in English, Chinese and Vietnamese. All were approved by the IRB at UPENN and PDPH.

Recruitment

Women were recruited, during regular clinic hours, in the waiting area of a District Health Center in Philadelphia, Pennsylvania. This health clinic offers family planning/prenatal clinic and approximately 40% of patients are Chinese or Vietnamese immigrants. All participants were given monetary compensation (\$25) for time and travel and a copy of their signed consent. The recruitment team consisted of four female staff members from the Penn Asian Health Initiatives (PAHI). They were trained in human subject research and in the techniques of conducting focus groups and in-depth interviews. All four individuals were bilingual in English and in either Mandarin or Vietnamese and all had advanced knowledge of Chinese or Vietnamese culture. In particular, the bi-lingual and bi-cultural Principle Investigator and project coordinator provided training to recruitment staff on institutional recruitment protocols and clinical research recruitment policies.

Recruiters approached women who they determined met eligibility criteria. Recruiters initiated the process in English and, depending on the response of the individual, either transitioned to speaking in the same language as the individual or signaled for another recruiter who spoke that language to continue the process in the spoken language. A recruiter presented the study to the individual using a script that was approved by the UPENN/PDPH-IRB. The script explained the study, the required action from the individual to participate, and the risks associated with participation. Individuals were informed of their right not to participate. Those who agreed to participate were presented a language-appropriate consent form for signature and given a copy of that document. Informed consent was confirmed verbally over the course of data collection.

Data Collection

The two most common Asian languages spoken in the US are Chinese and Vietnamese [27]. Among those who speak these, less than half speak English “very well” [28]. Interviews were conducted in the language preferred by the participants’ [29–31].

Interviews were audio-recorded and transcribed. The names and other identifiable information were deleted. Although our goal was to have multiple participants for each focus group, there were several occasions when only one person was able to attend. In such cases, we conducted a one-to-one interview.

Translation Procedures

Translators were Chinese or Vietnamese-speaking individuals with bi-lingual abilities and an in-depth understanding

of the respective cultures. The materials subjected to systematic translation were: recruitment and interview guides, audio-taped interviews, and self-report questionnaires. The process for translating written materials included the following steps. First, audio-tapes and written documents (e.g. scripts) were translated from the original language to the targeted language. Second, the translations were reviewed by a committee of experts (including bilingual/bicultural investigators) [32] for accuracy in meaning. Third, these documents were translated back to the original language to confirm the retention of the meaning and the context. [32] A different set of bilingual translators “back-translated” the materials from Chinese or Vietnamese to English. Fourth, a second review by experts and lay people was conducted to assess content validity, readability, etc. Finally, all linguistically discordant items were reconciled. The final materials accurately reflected the intent of the wording in the original language [33]. These materials were assessed for readability at the grade level (according to Flesch-Kincaid) of 6.8 [32].

Systematic back-translation is especially important. Back-translation is the evaluation of the proximity of the meaning of content from the source as compared to the translated version. This method is used to identify language conversion errors by translating back from the target language to the source language. Translating written words from one language to another can easily preserve the definitions of the words. However, translation that preserves the conceptual equivalence of whole sentences and paragraphs is more difficult and therefore benefits from back-translation. Capturing cultural context may also require changes to the format of an instrument and the interviewing procedure.

Measures

Data were collected using questionnaires and interviews. The patient-reported items included socio-demographics such as age, ethnicity, country of birth, and language skills/preferences; and selected behaviors such as (a) previous experience with biomedical research, (b) most recent Pap test, and (c) HPV vaccination history. The interview guide queried opinions about participating in biomedical research and bio-sampling.

Analysis

Text data were derived from 234 pages of transcription from 17 focus groups/interviews. Thematic content analysis of narrative data [34] developed themes using theory-driven or prior-research-driven methods and then applied a code to a “critical incident” or example of a conceptual construct, for example, a “barrier to participation” [35, 36]. Coding of narrative data was at two levels [37]. First level (open coding) was line-by-line to search for comments

related to experiences as research subjects, and the kinds of studies. The surrounding text was examined for links to specific feelings or judgments about the experiences. The second level of coding grouped the experiences and judgments into categories (themes) that matched the conceptual constructs of: (a) reasons to participate, (b) reasons to refuse participation, (c) enhancers of participation, and (d) approaches to recruitment [33]. We reexamined the surrounding text for links to specific statements that described ways to improve recruitment or enhance research participation among Asian women [38]. The statements were assigned a positive value (facilitating participation) or a negative value (hindering participation). Interviewers' and translators' impressions were noted and incorporated into the analyses.

Results

Sample Characteristics

Over a period of 20 weeks, a total of 231 Asian women were approached and invited to participate. Sixty-nine women agreed to participate. Thirty-nine women did not return for the qualitative study. Participation rate was 43% of those who initially expressing interest. Non-participation was mostly due to challenges in the scheduling of their office visits. Of the thirty who completed the study, 35% identified themselves as Vietnamese and 65% as Chinese. Ages ranged from 22 to 58 years with a mean age of 36.8 (SD 9.9 years). Three participants were born in the US. The remainder (N = 27) immigrated to the US at ages ranging from 12 to 52 years (mean age 29.6, SD 11.3 years). For additional characteristics see Table 1.

Preventive health behaviors varied across the sample. The majority (63%, N = 19) reported having had a least one pelvic exam, but 38% (N = 11) reported never having a Pap test, while one participant was unsure. Of those reporting having had a Pap test (N = 18), 94% (N = 17) were tested within the last 2 years. Forty percent (N = 12) of the women knew about the HPV Vaccine specifically by name but only one had been vaccinated. This project was the first encounter with research for over 86% of participants (N = 26). Of those who had been research subjects (N = 3), only 1 had provided a bio-sample and this was not blood.

Barriers to Participation in Research

Participants reported several important barriers to participating in research related to women's health issues and cervical cancer risk in particular. Major barriers to

Table 1 Characteristics of the study sample

Characteristics (N = 30)	Range, Mean (SD)
Age (years)	22–59, 36.8 (9.9)
Age at immigration (years)	12–52, 29.7 (11.3)
	N (%)
Ethnicity	
Vietnamese	9 (35)
Chinese	11 (65)
Spoken language	
Chinese	12 (40)
English	9 (30)
Vietnamese	9 (30)
Country of birth	
USA	3 (10)
Vietnam	9 (30)
China/Taiwan	8 (27)
Other (Mostly Indonesia)	10 (33)
English proficiency	
Very well	5 (17)
Well	10 (33)
Not well	13 (43)
Not at all	2 (7)
Preferred native language (non-English) for focus group discussion	18 (60)
Other demographics	
Employed for pay, part or full time	13 (43)
Has health insurance	6 (20)
Finished 12 years school	25 (83)
Some schooling in USA	18 (60)
Married, living with partner	20 (67)
Has a daughter	17 (68)
Has health insurance	6 (20)

participation were: limited time, mistrust, privacy issues, and inclusion of bio-sampling in the process.

The most frequently reported reason for non-participation in research was “lack of time, inconvenience, and competing interests” (see Table 2). This was a major inhibitor of participation in research even when alternative opportunities were conveniently presented.

Sixty percent (N = 18) of the participants reported a concern for their limited time at least twice in their interviews. The second most frequently reported reason for not participating in research was “mistrust of institutions and negative experiences” (30%, N = 9). Such mistrust was acquired vicariously through the experiences of others or through mass media illustrations of research. Recalling the experience of a family member, one woman stated that her relative “...was vaccinated while going to school. She had a serious fever. She's afraid now.”

Table 2 Psychosocial barriers to participation

Cases = number of Individuals who identified the concept

Conceptual category		
	Concepts	Cases (%)
Barrier to participation	Lack of time, inconvenience	18(60)
	Mistrust of Institutions, negative experience	9(30)
	Loss of privacy	6(20)
	Language not English	5(17)
	Specific fears: needles, cancer	5(17)
	Sexuality as topic	4(13)
	Confusing research with medical care	4(13)
	No personal relevance	3(10)
	Shame, stigma	2(7)
	Required to give blood sample	1(3)
	Long term participation	1(3)
	Diff concept of medicine	1(3)
Biosampling	Medications part of procedure	1(3)
	Need reason why	7(23)
	Too precious to give	4(13)
	Associated with sickness	3(10)
	Personally intrusive	3(10)

The simple act of interacting with strangers was the source of suspicion and mistrust, which is increased when language was a barrier or the bilingual recruiter and participant spoke different dialects. Three barriers to participation that were related to mistrust were “loss of privacy (20%, N = 6) and “traditional beliefs,” (20%, N = 6), and “sexuality as a topic” (13%, N = 4).

Privacy was an issue to all women but older women were reticent to discuss sexuality issues. Older participants tended to be more traditional or “isolationist” and not willing to be in research. Older women in this study did not elaborate on this barrier. However, the recruiters observed that when some older women arrived at the clinic with their spouses, they would look to them to sanction participating, prior to agreeing.

When asked about women’s health research that involved bio-sampling, participants expressed general reticence. Seventeen percent (N = 14) reported one or more specific concerns with bio-sampling. Among these 43% (N = 6) were Vietnamese, 36% (N = 5) were Chinese, and 21% (N = 3) further specified that they were Chinese-Indonesian. Six percent (N = 5) expressed two or more from among the following: “associated with illness,” “need a reason,” “personal intrusion,” “too precious to spare,” and “citing a negative experience of another.” Participants made a distinction between types of samples, such as blood

and other tissue. Four participants reported believing that blood, in particular, was “too precious to give” (13%, N = 4). Another knowledgeable participant knew that blood contained her DNA and therefore said she would hesitate to allow blood sampling.

Language Issues

Finally, language was confirmed as a barrier to participation. Language was inextricably linked to all other obstacles to participation in women’s health research (17%, N = 5). Participants named “lack of translated materials,” “feeling intimidated by English,” and the lack of translation of key words or terms. In addition, even if translation was attempted, differences in dialect or pronunciation could dissuade participation.

Enhancers of Participation in Women’s Health Research

Participants were asked to think about reasons why an Asian woman would be willing to enroll in research. Major enhancers to participation were: personal gain, benefit to other Asian women, and endorsement by a spouse.

The most frequently reported reason to enroll in women’s health research was for “personal gain” of medical help, information, and compensation (67%, N = 20). Personal gain was not entirely unexpected. Thirteen percent of participants made comments that suggested confluence of the aims of medical care and the aims of research (see Table 2). A second reason was for the “benefit of others” (40%, N = 12). This reason was often mentioned along with “personal benefit.” Of those who wished to benefit others, 60% specifically referred to Asian Americans. An altruistic rationale for participating was evident for both Chinese and Vietnamese participants. Participants reported that the likelihood of participating in research was increased if it was endorsed by a spouse (27%, N = 8), if compensation was offered (20%, N = 6), and if the approach was personalized (17%, N = 5).

Strategies to Enhance Recruitment

During focus groups and one-to-one interviews, participants were asked to offer their opinion on what could be done to improve a researcher’s success in enrolling Asian women in research. Four main approaches were suggested, (1) recruitment should be conducted in the language of the participants, (2) the content of the study materials should be personalized, (3) recruitment should be conducted at group events in the Asian community, and (4) recruitment should be conducted at the time of a previously scheduled medical visit. Each of the four approaches, in effect,

provided a solution for the principal barriers identified by the participants (see Table 3).

One suggested approach was to conduct recruitment efforts in the language of the participants. Fourteen percent ($N = 4$) explicitly recommended (1) preparing study materials in the language of the target group, (2) translating and using key phrases in English language study documents; and (3) using a recruiter who was fluent in the language of the group to be recruited. A young woman advised: "People like to hear their native language....even if you don't speak it perfectly, they are more comfortable and more trusting."

Participants suggested an approach to overcome the barriers of "mistrust and negative experiences". This could be done by using personalized recruitment materials. Participants noted that personal instructional content was a key contributor to improving success. Participants (30%, $N = 10$) suggested that recruitment materials should contain information on the "knowledge to be gained" and the "value of the research" to their reference group. Their comments illustrated the importance of also personalizing the process of research. To tap into the enhancer of the "desire to benefit self" and "benefit others," participants (17%, $N = 5$) suggested describing research projects at group events that are organized at churches or social meeting places for the purpose of providing health information.

Finally, as a way to reduce the barrier of "limited time," participants (13%, $N = 4$) suggested integrating study enrollment activities with routine or other medical visits. For example, one woman noted "they make it convenient because it's scheduled on my time."

Discussion

Our results illustrate that, with few exceptions, the barriers to participation in research are modifiable and enhancers are easily applied. A personal, individualized approach by the recruiter, in a relatively private locale, is preferred over an approach that is public. Our sample was already generally compliant with preventive health practices, and therefore did not necessarily represent women at highest risk or greatest need for intervention to improve their use of preventive health services. Even though our sample was not among those at highest risk, participants reported a main reason to be in research as "getting information for a family member." Therefore, these participants may deliver vital information to relatives who are at higher-risk for cervical cancer [39, 40].

Language as a barrier is not as easily modifiable as one may presume. Even though we were conducting our study in three languages, participants identified language as a

significant deterrent. Differences in dialect increased the cultural divide. The problem of dialect may be reduced if research staff is employed from the target population. This is a method used in community-based participatory research. Accommodating different dialects in a research study may not be practical or economically feasible unless the target group is extremely specific.

Two major reasons for non-participation were the lack of time and inconvenience. These reasons may reflect the considerable value placed by Asian Americans on the work ethics of high productivity and achievement [15]. Simply put, Asian women may consider their time as poorly spent on such activities as research. It is therefore essential that, if possible, an absolute value be associated with research participation. A person's availability and competing obligations are outside the purview of research teams. However, we have the ability to assist potential study participants to consider time spent as a research participant as "altruistic" and therefore, valuable.

The notion of altruism in the Asian cultures does not necessarily apply to all people. A main reason for participating in research was to "help our family and community." Participants in the study clearly specified that their beneficence was intended, first for individuals within their immediate family, next for the immediate circle of friends and associates, and then for the cultural group with whom they identified. The notion of the "greater good" radiated out from concentric circles of personal relationships with the nuclear family at the center and the larger world most distantly removed. Recruitment may be enhanced by framing the language of beneficence as directed to self, family, and for the greater good of their cultural social sphere.

Language-Specific Recruitment Materials

The work of Ahmad et al. [41] with women at risk for breast cancer, supports using written culturally-tailored, language-specific health educational materials to promote screening within a targeted population. To apply the recommendation of our participants we prepared key phrases, excerpted from interviews and matched these with enhancers to participation and validated by participants. These phrases, when translated and used in study materials, may increase enrollment of Asian Americans (see Table 4).

Combining strategies can enhance the probability of successful recruitment. The first and most important strategy is to remove the language barriers. All material should be prepared in the language of the target group. Encounters by recruiters and data collectors must be in the language of the participant and preferably in the specific dialect. Research participation will be enhanced if the benefits of research are specified as indirectly or directly related to one's family or their social sphere. For example, the

Table 3 Strategies and inclusion phrases

Strategy	Inclusion phrase	Chinese translation	Vietnamese translation
Begin invitation with a statement that emphasizes the problem for them	<i>The probability that Chinese women will develop cervical cancer is higher than [other ethnicities]</i>	Pronunciation: <i>Huayi nüxing huan shang zigongjingai de jilü bi qita minzu nüxing huan shang ci bing de jilü gao</i> 华裔女性患上子宫颈癌的几率比其他民族女性患上此病的几率高	Phụ nữ [Chung tộc] có nguy cơ mắc bệnh ung thư cổ tử cung cao hơn các phụ nữ khác
Appeal to desire to learn and improve oneself; personalize to self and family	<i>You will learn about being healthier and improve yourself</i>	Pronunciation: <i>nin hui xue dao zenyang yongyou geng jiankang de shenghuo bingqie xuehui zenyang tisheng shenghuo zhiliang</i> Characters: 您会学到怎样拥有更健康的生活并且学会怎样提升生活质量	Bà/cô/chị sẽ học thêm nhiều kiến thức để giúp tăng cường sức khỏe của mình
	<i>Prevention is better than treatment</i>	Pronunciation: <i>yufang bi zhiliao hao</i> Characters: 预防比治疗好	Phòng bệnh hơn chữa bệnh
	<i>You can bring a friend</i>	Pronunciation: <i>nin keyi dai pengyou gen nin yiqi lai</i> Characters: 您可以带朋友跟您一起来	Bà/cô/chị có thể mang theo bạn của mình
	<i>If you are curious this is a way to learn how to stay health and help your family</i>	Pronunciation: <i>ruguo nin gan xingqu dehua, zhe jiang shi yi zhong banfa lai baohu shenti jiankang he bangzhu ni jiaren</i> Characters: 如果您感兴趣的话, 那这将是一种办法来保护身体健康和帮助你家人	Nếu bà/cô/chị tò mò, đây là một cơ hội để học cách giúp bản thân và gia đình mình sống khỏe mạnh
	<i>Every answer you give is right</i>	Pronunciation: <i>nin ti chu lai de mei ge da'an dou dui</i> Characters: 您提出来的每个答案都对	Câu trả lời nào cũng đúng cả
	<i>Women like you have participated before</i>	Pronunciation: <i>gen nin you xiangsi qingkuang de nüxing canjia guo zheyang de huodong</i> Characters: 跟您有相似情况的女性参加过这样的活动	Nhiều phụ nữ như cô cũng đã tham gia
Reframe the value of the time spent	<i>When I have such knowledge I can understand and prevent for myself, friends, my family members, my sisters from sickness</i>	Pronunciation: <i>Dang wo you zhe lei de zhishi de shihou, wo jiu nenggou liaojie jibing yiji baohu wo ziji, wode pengyou, jiaren he jiemei de shenti jiankang</i> Characters: 当我有这类的知识的时候, 我就能够了解疾病以及保护我自己、我的朋友、家人和姐妹的身体健康	Nếu tôi có những kiến thức này, tôi có thể hiểu và phòng bệnh cho bản thân, bạn bè, người thân và chị em tôi
	<i>This is a useful way to spend your time</i>	Pronunciation: <i>zhe bu shi langfei shijian</i> Characters: 这不是浪费时间(Lit: This is not a waste of time)	Đây là một cách sử dụng thời gian bổ ích (note: I translated this as “
Appeal to ideal of personal choice	<i>It is your decision. You are in charge of your health</i>	Pronunciation: <i>ci xiang diaocha de jue ding quan zai nin shouzhong, nin de jiankang ye zhangwo zai nin shouli</i> Characters: 此项调查的决定权在您手中, 您的健康也掌握在您手里	Đây là quyết định của bà/cô/chị. Bà/cô/chị tự chủ trong việc chăm sóc cho sức khỏe của mình
Appeal to ideal of personal choice	<i>You will help other [language group V or C] women to be healthier</i>	Pronunciation: <i>nin hui bangzhu qita huayi funü tigao shenti jiankang</i> Characters: 您会帮助其他华裔妇女提高身体健康	Nếu tôi có những kiến thức này, tôi có thể hiểu và phòng bệnh cho bản thân, bạn bè, người thân và chị em tôi

Table 3 continued

Strategy	Inclusion phrase	Chinese translation	Vietnamese translation
Appeal to greater good	<i>Investment in the future of [language group]</i>	Pronunciation: <i>touru huaren de weilai</i> Characters: 投资华人的未来	
	<i>[V or C] women want and are looking for a brighter future</i>	Pronunciation: <i>huayi funü xiangyao erqie zhengzai xunzhao gengjia guangming de weilai</i> Characters: 华裔妇女想要而且正在寻找更加光明的未来	Phụ nữ Việt Nam mong muốn và đang tìm kiếm một tương lai tươi sáng hơn
	<i>You will help in the fight the rise of cervical cancer among [V or C] women</i>	Pronunciation: <i>Ni hui dui kangji zai huayi nüxing zhong yuelaiyue liuxing de gongjingai zuochu gongxian</i> Characters: 您会对抗击在华裔女性中越来越流行的宫颈癌做出贡献	Bà/cô/chị sẽ giúp ngăn ngừa bệnh ung thư cổ tử cung phổ biến ở phụ nữ Việt Nam
	<i>[language group-V or C] women need to protect their health</i>	Pronunciation: <i>huayi funü xuyao baohu ziji de shenti jiankang</i> Characters: 华裔妇女需要保护自己的身体健康	
Assure privacy	<i>All results will be kept private, we ensure that the results of the survey will not be leaked to a third party</i>	Pronunciation: <i>suoyou jieguo hui baomi, women baozheng bu hui ba diaocha jieguo xielou gei di san fang</i> Characters: 所有结果会保密, 我们保证不会把调查结果泄露给第三方	Cuộc nghiên cứu này sẽ được giữ kín, không ai biết được

“greater good” is the good of their community of family, friends, Asian subgroup, and so on, in that order.

Issues to Monitor

Participants were somewhat-to-very confused about the difference between research and medical care. As a strategy, several participants suggested combining medical visits with research enrollment. The suggestion to integrate research study enrollment activities with routine or other medical visits may be efficient and save time, but may also contribute to a woman’s confusion. This may ultimately compromise the integrity of informed consent.

The participants’ reactions to the addition of bio-sampling, was negative. The negative reaction was especially strong if bio-sampling included giving blood. The most poignant objection was fueled by the belief that blood was “too precious to spare.” The reason most often reported, however, was they were not given “a good reason to do so.” This objection may be easily reversed by a concerted effort to explain the ultimate value of such research to self, family, and other Asian women “like herself.”

Limitations

This pilot study allowed us to identify limitations that may need to be addressed before designing and conducting larger definitive clinical trials. The proportion of participants of Chinese ethnicity (65%) challenges our ability to

apply findings to women from ethnic backgrounds not included in the sample. The range of ages for our participants was wide, making it difficult to make general statements about any particular age group, but this diversity of age enabled us to capture a broader view of the experiences of the study population.

The initial use of focus groups for data collection was limiting. We found that the richness of the transcript data was quite variable, with some of the focus groups being notably cursory in comparison to individual interviews. We attribute this to the sensitive, private nature of the topic. In addition, the reticence by focus group participants to elaborate on their comments resulted in the interviewers suggesting potential responses and asking if participants might agree. It is possible that this approach either helped participants “find the appropriate words” or implied the “correct” response.

While well suited for an exploratory pilot study and an excellent source of first-hand experiences from participants, collecting data using focus groups has its limitations. It may be cumbersome, time consuming and is not appropriate for clinical trials. The research design must dictate the most appropriate data collection strategy after advantages and disadvantages are weighed. Group interviews may provide a community forum for subjects to discuss women’s health issues and medical research, but they also lend to automatic agreement among members when one participant distinguishes herself as well-spoken or highly informed. Group settings can provide psychological support for a woman

Table 4 Key words and terms in English with usage in Mandarin Chinese and Vietnamese

Category	English	Mandarin Chinese	Vietnamese
Introductions	Interpersonal Reference: You	<p>Usage: If the interviewee is older than the interviewer, begin with the formal form of address, and adjust based on what the respondent seems more comfortable with. If the interviewee is the same age as the interviewer, this approach is inappropriate. Begin with the informal you.</p> <p>Formal “you” Word/Phrase: 您 Pronunciation: Nin</p> <p>Informal “you” Word/Phrase: 你 Pronunciation: Ni</p>	<p>Usage: “You” as a salutation is in relation to the age of person speaking or age of parents or person speaking</p> <p>Based on person being addressed:</p> <p>You: female same age as self Word/Phrase: Chi Pronunciation: Chee</p> <p>You: female younger age than self Word/Phrase: Em (literally, little sibling) Pronunciation: Ehm</p> <p>You: younger woman Word/Phrase: Cô (literally, younger aunt) Pronunciation: Koh</p> <p>You: woman older than self Word/Phrase: Bác (literally, older aunt) Pronunciation: Back</p> <p>You: Elderly woman (two generation spread) Word/Phrase: Bà (literally, grandmother) Pronunciation: Bah</p>
	Interpersonal Reference: I or self referral	<p>I (me) Word/Phrase: 我 Pronunciation: wo</p>	<p>Usage: “I” as a self-referral is in relation to the age of person being addressed. The literal translation of “I” is tôi, but it is usually used in very formal settings, rarely in conversation.</p> <p>Based on person being addressed:</p> <p>I: if addressing person approximately same age Word/Phrase: Em (literally, little sibling) Pronunciation: Ehm</p> <p>I: If addressing older person Word/Phrase: Con (literally, your child) Pronunciation: Cawn</p> <p>I: if addressing much older person (two generation spread) Word/Phrase: Cháu (literally, your grandchild, niece, or nephew) Pronunciation: Jow</p>
	Hello	<p>Hello: If addressing a woman considerably (at least 20 years) older than you Word/Phrase: 阿姨, 您好!(Literally, Auntie, hello!) Pronunciation: A’yi, ninhao!</p> <p>Hello: If addressing a woman the same age as you or slightly older (option 1) Word/Phrase: 你好 Pronunciation: Ni hao</p> <p>Hello: If addressing a woman the same age as you or slightly older (option 2) Word/Phrase: 大姐你好 (literally, older sister, hello) Pronunciation: Dajie, nihao</p> <p>Hello: If addressing a younger female Word/Phrase: 你好 Pronunciation: Ni hao</p>	<p>Standard: Hello...[insert name] Word/Phrase: Chào... Pronunciation: Chow...</p> <p>Highly Formal: Hello Word/Phrase: Xin chào... Pronunciation: Seen chow...</p>

Table 4 continued

Category	English	Mandarin Chinese	Vietnamese
Study-related terms	Research Study or Survey	<p>Usage: People were more receptive to the term Research study/survey (as opposed to “Medical Research”) as this was less threatening and less confusing.</p> <p>Medical Research Word/Phrase: 医疗研究 Pronunciation: Yiliao yanjiu</p> <p>Research study/survey Word/Phrase: 研究调查 Pronunciation: yanjiu diaocha</p> <p>Study and survey Word/Phrase: 调查 Pronunciation: Diaocha</p>	<p>Usage: The term “medical research” is less intimidating than “scientific research,” which implies greater complexity.</p> <p>Medical research Word/Phrase: Nghiên cứu y khoa Pronunciation: knee-in kew ee khwah</p> <p>Research Study Word/Phrase: Việc học để tìm hiểu (literally, the act of studying to understand something) Pronunciation: Vick hock day team hue</p> <p>Study and survey Word/Phrase: Nghiên cứu khảo sát Pronunciation: Knee-in kew khow sat</p> <p>Scientific Research Word/Phrase: Nghiên cứu khoa học Pronunciation: Knee-in kew khwah hock</p>
	Would [you] be interested in this research? Why, why not?	<p>Word/Phrase: 您会对这个研究感兴趣吗? 为什么? 为什么不? Pronunciation: Nin hui dui zhege yanjiu gan xingqu ma? Weishenme? Wei shenme bu?</p>	<p>Word/Phrase: [Chi/cô/bà] có muốn tham gia vào nghiên cứu này không? Tại sao có? Tại sao không? Pronunciation: [Chee/Koh/Bah] caw moo-un tam ya vow knee-in kew nai khoh-ng?</p>
	Do you want to participate to help the greater (Vietnamese) community?	<p>Word/Phrase: 您愿不愿意为了帮助华人群众而参加此项活动? Pronunciation: Nin yuan bu yuanyi wei le bangzhu huaren qunzhong er canjia ci xiang huo dong?</p>	<p>Word/Phrase: [Chi/cô/bà] có muốn tham gia để giúp cộng đồng (người Việt) mình không? Pronunciation: [Chee/Koh/Bah] caw moo-un tam ya day yoop koh-ung doh-ung (new-oy Vee-et) koh-ung?</p>
	Do you want to participate to help the family?	<p>Word/Phrase: 您愿不愿意为了帮助您的家人而参加此项活动? Pronunciation: Nin yuan bu yuanyi wei le bangzhu nin de jia ren er canjia ci xiang huo dong?</p>	<p>Word/Phrase: [Chi/cô/bà] có muốn tham gia để giúp gia đình? Pronunciation: [Chee/Koh/Bah] caw moo-un tam ya day yoop ya ding?</p>
	Do you want to participate to help future generations?	<p>Word/Phrase: 您愿不愿意为了帮助后代而参加此项活动? Pronunciation: Nin yuan bu yuanyi wei le banzhu hou dai er canjia ci xiang huodong?</p>	<p>Word/Phrase: [Chi/cô/bà] có muốn tham gia để giúp thế hệ tương lai? Pronunciation: [Chee/Koh/Bah] caw moo-un tam ya day yoop tay hay too-ung lie?</p>
	Would you be willing to participate in this study to help us, the recruiters of this study?	<p>Word/Phrase: 您愿不愿意为了帮助我们调查员而参加此项活动? Pronunciation: Nin yuan bu yuanyi weile banzhu women diaocha yuan er canjia ci xiang huo dong?</p>	<p>Word/Phrase: [Chi/cô/bà] có thể giúp [chúng em/ chúng cháu] tham gia vào nghiên cứu khoa học này để hiểu biết thêm về bệnh HPV và bệnh ung thư cổ tử cung ở phụ nữ? Pronunciation: [Chee/Koh/Bah] caw tay yoop [choo-ng ehm/choo-ng chow] tahm ya va-oh knee-in kew khwah hock nai day hee-ew bee-it tame vay bun oong too koh too coo-ng uh foo nu?</p>
	What would you like to know?	<p>Word/Phrase: 参加这个调查之前,您会想要知道什么信息? Pronunciation: Canjia zhege diaocha zhi qian, nin hui xiangyao zhidao shenme xinxi?</p>	<p>Word/Phrase: [Chi/cô/bà] muốn tìm hiểu những gì? Pronunciation: [Chee/Koh/Bah] moo-un team hee-ew nyung yee?</p>
	A study to understand the prevalence and potential treatment of a disease.	<p>Word/Phrase: 为了进一步理解一种疾病的流行程度和治疗方法举行的调查 Pronunciation: Wei le jin yi bu lijie yi zhong jibing de liuxing chengdu he zhiliao fangfa juxing de diaocha</p>	<p>Word/Phrase: Việc học để tìm hiểu thêm kiến thức về một căn bệnh và cách chữa. Pronunciation: Vee-ick hock day team hee-ew tame keen took vay moat kun bun vah kike chew-ah</p>

Table 4 continued

Category	English	Mandarin Chinese	Vietnamese
	Genital	Word/Phrase: 生殖器 (literally: reproductive organs) Pronunciation: sheng zhi qi	Word/Phrase: Vùng sinh dục chỗ cấm (literally, private place) Pronunciation: Voo-ng sing yook choh kum
	Pelvic exam.	Gynecologic Exam Word/Phrase: 妇科检查 Pronunciation: fu ke jiancha Women's Exam Word/Phrase: 妇人检查 Pronunciation: fu ren jiancha	Gynecologic Exam (Exam to check the uterus and female reproductive organs for abnormalities) Word/Phrase: Xét nghiệm để xem có gì bất thường trong tử cung và vùng sinh dục phụ nữ. Pronunciation: Set knee-im day sem caw yee but too-ung chong too coo-ng vah voo-ng sing yook foo nu Women's Exam Word/Phrase: Khám phụ khoa Pronunciation: Khahm foo kh-wah
	Pap Smear	Usage: Some women are more familiar with and understood the English term “Pap smear” than with a Chinese translation, start with English term “Pap smear.” Both in script and (particularly for mainland Chinese) in pronunciation, the phrase contains a word, 涂片 (“tupian”), that sounds exactly the same as the word for picture, 图片 (“tupian”). Word/Phrase: 子宫颈抹片检查 (Taiwan) 子宫颈涂片检查 (mainland) Pronunciation (Taiwan): Zigongjing Mopian Jiancha (literally “Cervix wipe test”) Pronunciation (Mainland): Zigongjing Tupian Jiancha (literally “Cervix scrape test”)	Pap Smear Word/Phrase: phết tế bào cổ tử cung (medical term, literally “wiping cells of the cervix”) Pronunciation: fate tay bow koh too coo-ng Procedure to look for cancerous cell in the cervix Word/Phrase: Xét nghiệm để tìm tế bào bệnh ung thư ở cổ tử cung. Pronunciation: Set knee-im day team tay bwo ben oong too uh koh too coo-ng
	Have you ever had a Pap test before?	Pronunciation: a. qingwen, nin you meiyou cengjing jieshouguo zigongjing mopian jiancha? OR b. qingwen, nin you meiyou jieshouguo zigongjing tupian jiancha Characters: a. 请问, 您有没有曾经接受过子宫颈抹片检查? OR b. 请问, 您有没有曾经接受过子宫颈涂片检查?	Word/Phrase: Trước đây chị/cô/bà đã từng xét nghiệm Pap smear chưa?
	Does anyone have questions about what we are about to do now?	(Formal) Pronunciation: Xianzai, shifou you ren dui women jijiang kaishi de huodong you shenme wenti? Characters: 现在, 是否有人对我们即将开始的活动有什么问题? (Informal) Pronunciation: Xianzai, you mei you ren dui women kuai yao kaishi de huodong you shenme wenti? Characters: 现在, 有没有人对我们快要开始的活动有什么问题? Note: The words for “about to begin” (即将开始) and “does anyone” (是否有人) are very formal, and I have given an alternative that is less formal, which is what I used.	Word/Phrase: Có ai có câu hỏi gì về việc chúng ta sắp làm không?

Table 4 continued

Category	English	Mandarin Chinese	Vietnamese
	Who, when, why?	Pronunciation: shei? Shenme shihou? Wei shenme? Characters: 谁?什么时候?为什么?	Word/Phrase: Ai, khi nào, tại sao?
	Again, thank you for participating in this study.	Pronunciation: Zai ganxie nin lai canjia zheci diaocha. Characters: 再感谢您来参加这次调查	Word/Phrase: Một lần nữa, xin cảm ơn/cảm ơn chị/cô/bà đã tham gia nghiên cứu này.
Other terms	Your family members	Word/Phrase: 您的家人 Pronunciation: Nin de jia ren	Word/Phrase: Thành viên trong gia đình Pronunciation: tang vee-in chong ya ding Alternative (“relatives”) Word/Phrase: người thân Pronunciation: new-oy tunn
	Community	The Community of Chinese people Option 1 Word/Phrase: 华人群众 Pronunciation: huaren qunzhong The Community of Chinese people Option 2 Word/Phrase: 华人社会 Pronunciation: huaren shenhui (shenhui = lit. “society”)	Your community Word/Phrase: Cộng đồng của bạn Pronunciation: Coe-ng Doe-ng coo-ah ban Note: if the recruiter is of the same ethnicity as the person being recruited, it is more effective/natural to frame “ your community” as “ our community”

commenting on sensitive and personal issues, such as HPV and Pap tests. If the woman’s response garners positive support and acknowledgement from fellow subjects, she may feel reassured in this environment. Other women may perceive this comfort and, in turn, feel more confident in expressing their opinions. In addition, the group interview creates a more dynamic environment for discussion. On the other hand, if a participant perceives that other women are reacting negatively to her comments, she will be less likely to further contribute her opinions. Introverted women may simply affirm the comments of extroverted participants rather than expressing their individual opinion. It is widely recognized that Asian Americans will agree with their family and community to avoid dissension and isolation.

One-on-one interviews may produce more honest responses to questions on sensitive, personal topics. The alternating of focus groups with one-to-interviews corrected the influence of the directed prompts. In general, one-to-one in-depth interviews were more productive of themes and an open exchange of opinions than were focus group interviews. The success of one-to-one encounters punctuates the recommendation that future research recruitment efforts should be as private and personal as possible.

While participants initially felt uncomfortable discussing gynecological issues, this discomfort subsided as discussion proceeded. A majority of the women were

sexually active or had had a pap smear (this information should be verified). They were, therefore, familiar with and more or less willing to discuss their experience with gynecological exams. Subjects demonstrated apprehension in discussing the sexual health of their daughters. Subjects assumed that their daughters were not sexually active and therefore did not need the HPV vaccine. Also, they presumed that vaccination might give license to promiscuity.

In addition, comfort levels are also dependent on the ability of the interviewer to create a rapport with the subject. Unlike group interviews, individual interviews will not illustrate the importance of family and community in decisions regarding sexual health and medical research. Since Asian Americans significantly value community relationships, individual interviews may not capture the contribution of this socio-cultural factor.

Finally, because the sample size is small ($n = 30$) one must be cautious about generalizing to the larger population and thus presents the need to test these findings in clinical trials.

Future Directions

The strategies generated from our work can be employed to facilitate recruitment of Chinese and Vietnamese American women for cancer control research. This pilot

provides practical guidelines and specific techniques for recruiting Asian women into cancer control research. The next steps should test the extent to which the inclusion of key phrases and approaches may improve recruitment for research involving bio-sampling. The cultural competency of research recruiters is essential to engage the understudied population of Asian American women into research. Culturally appropriate research will require additional resources and additional costs of time and money. However, the ultimate benefit to science from improved validity and generalizability will outweigh these costs.

A long term application of this study is to increase participation by Asian women in medical research, and to explore the transferability of strategies identified in the tables. Among the recommended strategies, one must first remove language barriers and preferably use specific dialects during recruitment, enrollment and data collection. Second, one must specify if benefits are indirectly or directly related to the family or cultural group. Researches should expect that potential participants will be highly motivated to enroll in a study with these benefits. The strategies proposed by this pilot should first be tested among a similar population of women who are sought as participants in research involving prevention and early detection of cervical cancer. The phrases contained in both Tables 3 and 4 can be readily used in future studies, even if the research study recruiter does not speak fluently Chinese or Vietnamese. One may simply point to the corresponding statement on the table to ask the question or give instructions.

Berger and Luckman [42] describe the social construction of reality as the process in which persons and groups interacting, together form, over time, concepts or mental representations of each other's actions. These concepts eventually become habituated into reciprocal roles played by the actors in relation to each other. Asian women at risk for cervical cancer play an important role in the process of creating scientific reality. Our knowledge and experience as clinicians and researchers methodically combined with their knowledge and beliefs about their health needs and culture may help embed research participation into the fabric of their culture society. The social group of Asian women will ultimately benefit from the individual's participation in scientific inquiry.

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