

# Using qualitative methods to develop a contextually tailored instrument: Lessons learned

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## ABSTRACT

**Objective:** To develop a population-specific instrument to inform hepatitis B virus (HBV) and human papilloma virus (HPV) prevention education and intervention based on data and evidence obtained from the targeted population of Khmer mothers reflecting their socio-cultural and health behaviors. **Methods:** The principles of community-based participatory research (CBPR) guided the development of a standardized survey interview. Four stages of development and testing of the survey instrument took place in order to inform the quantitative health survey used to collect data in stage five of the project. This article reports only on Stages 1-4. **Results:** This process created a new quantitative measure of HBV and HPV prevention behavior based on the revised Network Episode Model and informed by the targeted population. The CBPR method facilitated the

application and translation of abstract theoretical ideas of HBV and HPV prevention behavior into culturally-relevant words and expressions of Cambodian Americans (CAs). **Conclusions:** The design of an instrument development process that accounts for distinctive socio-cultural backgrounds of CA refugee/immigrant women provides a model for use in developing future health surveys that are intended to aid minority-serving health care professionals and researchers as well as targeted minority populations.

**Key words:** Hepatitis B virus, human papillomavirus, cambodian americans, qualitative method, cognitive interview, instrument development, vaccination behavior

## Introduction

The HIV, hepatitis B virus (HBV), and human papillomavirus (HPV) share a common profile in that each virus is

transmitted primarily through sexual contact. However, HBV is 100 times more infectious than HIV<sup>[1-6]</sup> and prevalence of HBV among Asian Americans and Pacific Islanders (AAPIs) range from 4% to 15%, which is more than 10 times higher than those of the general population.<sup>[7-10]</sup> Unlike HIV, both HBV and HPV are vaccine preventable diseases.<sup>[1-4,6,11]</sup> However, HBV and HPV vaccinations among AAPIs have been low compared with other racial/ethnic groups<sup>[3,12-17]</sup> and there is limited information related to vaccination and cancer prevention behavior for this diverse, minority population.

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Despite a decrease in acute HBV infection, the prevalence and burden of chronic HBV infection remains substantially high in the US. An estimated 0.8-1.4 million people in the US have chronic HBV and of those people, 47%-70% were born in other countries.<sup>[1,3,7,8,16]</sup> Chronic HBV is a major health disparity among AAPIs. Half of those with Chronic HBV are AAPIs, 74% of whom are foreign-born.<sup>[3,7,8]</sup> In contrast to the US pattern of transmission through infected needles and blood during adulthood, the majority of Asian Americans with chronic HBV become infected early in childhood by transmission from mother to infant,<sup>[1,3,16,18-21]</sup> and are, therefore, at much greater risk of developing long-term complications of the infection by the 4<sup>th</sup> or 5<sup>th</sup> decade of life.<sup>[22-24]</sup>

Human papilloma virus is the most common sexually transmitted infection, with approximately 75% of sexually active adults acquiring one or more genital HPV types at some point in their lifetimes. Cervical cancer, a gender-specific disease, is casually related to infection by HPV: Approximately 70% of cervical cancers are caused by HPV 16/18. Based on their association with cervical cancer and precursor lesions, HPV can also be grouped in high risk and low-risk HPV types. HPV types 16 and 18, types 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 68, 73, and 82 are considered carcinogenic, or high-risk types; three types (26, 53, and 66) are considered probably carcinogenic; 12 types (6, 11, 40, 42, 43, 44, 54, 61, 70, 72, 81, and CP6108) are considered low-risk types. However, only a few people know they are infected since noticeable symptoms are seldom produced.<sup>[4,6,11]</sup>

Although the incidence and mortality of cervical cancer declined in the US due to the increased cancer screening and vaccination programs,<sup>[25,26]</sup> the cervical cancer rate is still higher among ethnic minority and foreign-born women in the US.<sup>[26-31]</sup> Cervical cancer places a particularly heavy burden on Southeast Asian American women as the rates of cancer incidence are 41 per 100,000 versus 8.7 for white, 13.2 for blacks and 16.2 for Hispanic.<sup>[27]</sup> Despite evidence that cervical cancer can be prevented with vaccination and screening, studies show that the incidence of cancer screening is very low and mortality from cervical cancer is notably high among women of color, foreign-born, and those with limited access to care.<sup>[11,25-28,32-34]</sup>

Cervical and liver cancers are the only two that can be prevented through vaccinations and cancer screenings. Existing data show significant variability in incidences of HBV and HPV vaccination, liver and cervical cancer and mortalities related to these diseases among AAPI subgroups<sup>[13-15,25-36]</sup> and the variation among AAPI

groups indicates the importance of studying these groups separately. Healthy people 2020 highlights the importance of addressing the social determinants of health by recognizing social and physical environments that promote good health for all. To support evidence-based practice, it is essential to develop and validate measures of variables important for HBV and HPV prevention behavior. However, aggregating AAPI ethnic groups with diverse socio-cultural backgrounds ignores the heterogeneity of these subpopulations and obscures the unique problems faced by individual ethnic groups. In particular, to understand mothers' perceptions, understandings, and parenting roles related to HBV and HPV infection prevention for themselves and their daughters is crucially important. Therefore, the purpose of this study is to develop a disease- and population-specific instrument for HBV and HPV prevention education based on data and evidence obtained from the target population reflecting their social and cultural determinants of HBV and HPV vaccinations.

This study targeted Cambodian Americans (CAs) for the following reasons:

1. CAs, who are not a major AAPI group in terms of population size, were not included in most data analyses specifically because they were classified as Southeast Asian or others;
2. Literature review revealed a lack of culturally and linguistically sensitive measures of socio-cultural and individual factors associated with HPV and HBV prevention behavior;
3. They are among the largest AAPI populations in Massachusetts (MA), the site of the study, and have a significant proportion of their population with linguistic barriers<sup>[15,37-39]</sup> that may influence the reporting of health disparities;
4. Cultural targeting required focusing on one ethnic group at a time;
5. And the project team developed trusting, respectful relationships with relevant CA individuals and organizations based on prior research and community-based collaborations.

## Materials and Methods

### *Socio-cultural context and setting of the study*

Lowell, MA has the highest proportion of residents of Cambodian origin of any city in the US. Estimates of the total number of Cambodians living in Lowell typically range from 25,000 to 35,000 based on the number of CA owned businesses, Cambodian temples, and the number of CA students at Lowell High School who account for one-third of its enrollment (CA students represent 1400 of more than 4000 students in grades nine through twelve).<sup>[37-39]</sup>

CAs began arriving in the US as refugees after surviving the brutal rule of the Khmer Rouge in Cambodia from 1975 to 1979 when 1.7 million people - close to 30% of the country's population - died from starvation, execution, torture, forced labor, and illness. Many CAs lived in refugee camps before resettling in the US where they often faced starvation, disease, and violence.<sup>[40-43]</sup> These experiences led to a high rate of posttraumatic stress disorder and depression that continue to influence current CA health and health behaviors.<sup>[44,45]</sup> More than 70% of CAs are refugees and immigrants, many of whom face the task of developing networks and social relationships with members of their ethnic group and with the mainstream population in their postmigration environment. The 2010 US Census indicated that CAs had the highest poverty rate and the highest proportion of linguistic isolation among all AAPI groups that year with over 90% speaking Khmer at home.<sup>[37]</sup>

### Overview of steps to develop the instruments

To develop and test a theory-based culturally relevant instrument to inform and guide HBV and HPV prevention education and intervention, a community-based participatory research (CBPR) design was utilized. The CBPR involved five stages:

1. Conduct qualitative interviews to inform the development of a quantitative instrument;
2. Select items;
3. Translate the instrument;
4. Conduct "cognitive interviews" to establish that respondents are able to understand the intent of the question and answer the questions using the categories provided, and that these questions and answers accurately reflected their experience; and
5. Conduct full scale survey. This article covers only Stages 1-4 of the project [Table 1].

The study protocol was approved by the Institutional Review Board of the University of Massachusetts Boston.

**Table 1: Instrument development process**

Stages	Activities
Pre-stage: Literature review	Conduct literature review Confirm that no tools exist Develop theoretical frame
Stage 1: Qualitative studies	Conduct focus group and individual interview Individual coding and opening coding Rexam the theoretical framework
Stage 2: Select items	Develop item pools Panel discussions Develop a pilot instrument
Stage 3: Translate	Individual translations Panel discussion
Stage 4: Cognitive interviews	Train the interviewers Conduct cognitive tests Develop the final version of instrument

### Using a community-based participatory approach

The proposed project was conducted by a multi-disciplinary team of investigators representing academic institutions and the CA community. Since the majority of CAs go to the temple, ethnic grocery markets, and ethnic community health clinics, we designed a community-based sampling method that is culturally and scientifically appropriate for CAs. Before beginning recruitment, culturally relevant strategies were developed by working with local Khmer researchers and community health leaders (CHLs). Several media-based strategies were used through Khmer language radio and television, bilingual flyers distributed to Khmer businesses, grocery stores, community health clinics, and temples. The main ad campaign to the community emphasized the importance of collecting data from CAs for CAs in terms of "Data is Power."

#### Existing cambodian american community capacity

Cambodian Americans in MA have access to substantial community education capacity in Lowell through institutions such as the Metta Health Center of the Lowell Community Health Center, which was established in 2000 to address the ethno-cultural and institutional barriers to health and mental health care for Southeast Asian communities in Lowell. At the Metta Health Center, 90% of the staff are from Cambodia or Laos and more than 70% of the 4000 clients are CAs. The Metta Health Center provides health services, health advocacy, and health education as well as social services, and leads a CDC-funded REACH 2010 (Racial and Ethnic Approaches to Community Health) partnership with CAs and other Cambodian-run health outreach organizations to provide health advocacy and education about heart disease and diabetes. The Metta Health Center served as the anchor site for participant recruitment, research team meetings, and data collection for this project.

From the outset, academic and community partners cross-trained to enhance the capacity of the research team to implement CBPR approaches. This was based on acknowledgment that both community and academic partners are experts. CHLs led the cultural training since they better reflect the community's view and understanding about the health survey and can explain the culturally and linguistically appropriate survey interview process, while academic research team members led the training in relation to general interview skills for standardized survey administration. The first step was to mobilize key individuals and organizations in the CA communities in MA. CHLs, including physicians, registered nurses, translators, patient navigators, health administrators, school



counselor, and educators were involved in various phases of the process and served as key informants. Consensus was built between all major stakeholders, especially CHLs, to ensure the development of an instrument that was socially, culturally, and linguistically appropriate for the target populations.

As the design and implementation of the instrument continued to evolve, modifications were made based on experiences and input from the participants including CHLs, interviewers, and study participants. As one CA CHL commented, “It is the first kind of study of Khmers (Cambodians) involving them in the research process and brings our knowledge that is appreciated and treated as valuable sources.” The research team emphasized developing solid relationships with the communities as the most effective way of developing the instrument.

### *Theoretical framework*

By understanding the socio-cultural world in which the participants live and work, including participants’ views of the phenomena being studied, we proposed a theoretical framework based on the Network Episode Model (NEM)<sup>[46,47]</sup> which explains how individuals come to recognize and respond to illness and health and use healthcare services. The NEM was revised (rNEM) based on the qualitative studies in Stage 1 of the study described below. The rNEM was tailored to the diseases and the CA population,<sup>[42]</sup> facilitated the application and translation of abstract theoretical ideas into real-world culturally-relevant health behavior and helped to develop contextually relevant measures. In rNEM, health experience is conceptualized as an interactive social process that is shaped by the participants’ social networks rather than by a deterministic response. Four constructs have been identified as important for examining HBV and HPV prevention behavior: Socio-cultural context, social networks, individual factors, and health behaviors. In this article, we regard health behavior as the receiving of the HBV and HPV vaccination, individual factors as the knowledge-base and attitudes of each participant, and the social networks as stable patterns of interactions among people. Parents are conceived as the core social network influencing their children’s perception of HBV and HPV vaccination. Culture-specific knowledge about HBV and HPV infection is defined as a dimension of the individual factors that influence participants’ perception of HBV and HPV vaccination.

### *Qualitative study (Stage 1)*

The two focus groups mixed both male and female CHL participants (one group of 7 participants and one group

with 10 participants), and were conducted at community health center sites in Lowell and Lynn, MA. In-depth individual interviews with six CA mothers who have daughters aged 12-17 were conducted following the focus groups. A purposeful sampling method was utilized for focus groups and individual interviews. Interviews were conducted in either English or Khmer or a combination of both languages depending on the preferences of the participants. Interview guides were used and all interviews were tape recorded, and transcribed. Khmer interviews were audio translated into English and then transcribed. Consistent with the process of instrument development with understudied minority groups, item generation reflecting participants’ cultural and linguistic experiences is a critical step. Hence, the qualitative interview questions were designed to elicit information about participants’ perceptions or understanding of HPV and HBV infection and prevention behaviors and direct and indirect experiences with these diseases within their local settings. To analyze the contextual data, the researchers assigned conceptual codes to passages of text. An open coding meeting with coders, a Khmer consultant (PC), CHL (SP), and RA (SSA), was conducted to debrief and share the coders’ perspectives and approaches to the data. Data from this stage informed our contextualized item generation for a quantifiable survey instrument.

Cambodian American mothers’ narratives revealed the influence of a complex set of knowledge-based, attitudinal and socio-cultural factors that influenced their parenting and health behaviors in their individual settings. Though most participants in the individual interviews had never heard the terms HBV and HPV before the interview, they thought that hygiene, particularly exposure to dirty water during the Khmer Rouge regime or in the refugee camps, was inextricably related to virus infections.

The qualitative data revealed that there were language barriers among CAs beyond simply not understanding English because there are no words in Khmer (Cambodian) language for some medical and anatomical terms, including hepatitis B, cervix, Pap smear, and cervical cancer. Different participants, therefore, understood the interview questions differently. In addition, cultural issues related to reproductive or sexual organs and sexually transmitted diseases (STDs) were identified. The CHLs recommended the use of a diagram or photographs in conjunction with the questionnaire since even the Khmer data collectors did not know the words for HBV and HPV and other terms related to sexual organs or STDs, but they could utilize the diagram of the cervix and the diagram of HBV or HPV. Overall, the qualitative data from these narratives enabled

the project team to construct the health survey items pools and to develop contextually relevant measures.

### Item selection (Stage 2)

The objective of this stage was to ensure not only content validity, but also cultural sensitivity. Item selection is a critical step in instrument development. Often, the psychometric literature focuses on the reliability and validity of items, rather than how the item emerged or evolved.<sup>[48]</sup> Our focus, however, was to select linguistically appropriate and culturally sensitive items for the non-native English speaking target population. Items related to the theoretical constructs were extracted from qualitative data and checked for duplication with the existing instruments. If items were duplicated, then the qualitative data-generated item was retained and the item from the existing instrument was dropped.

A review panel consisting of CHLs, researchers, and interviewers who were content experts was convened to assess all of the items or statements qualitatively and quantitatively based on a four point rubric in order to rank the degree of importance for each item to establish accruing empirical evidence of content validity of the construction criterion.<sup>[49,50]</sup> They concluded that the survey was too long with too many socio-cultural/demographic questions, and recommended limiting such questions so as to not discourage potential CA mothers from participating in the study. In addition, they constructed the instrument format, selected culturally relevant words and established scaling methods. Measures of demographic factors, such as marital status, education, and birth place from the Behavioral Risk Factor Surveillance System were reviewed to check the relevance to CAs. However, the panelists thought that these measures did not account for the socio-cultural dimensions of CAs. For example, measures of educational attainment did not account for the socio-historical reality that a majority of CA mothers did not receive formal education during their Khmer Rouge or refugee camp years. Therefore, we added categories to reflect the participants' historical context. Panelist-suggested new measures based on qualitative data are included in Table 2. More than one third of items for knowledge [Tables 3 and 4] were derived from the qualitative data in Stage 1. The need to include these items suggests that existing instruments are culturally inadequate to measure the response of CA mothers.

### Translation of the instruments (Stage 3)

One long-standing view of the relationship between language and culture proposes that the structure of a language determines the way in which speakers of the

language view the world. Although culture does not determine the structure of a language, it influences how a language is used.<sup>[51,52]</sup> Taking this into account, a multi-phased procedure for translating the instrument was utilized as follows:

1. Selected items were independently translated by two bilingual CHLs;
2. The translated draft was checked for agreement; and
3. Each item was then discussed by the panel.

The research team took into account the varying perceptions and expressions of words in social context and utilized multi-phased translation procedures that have been shown to be culturally, linguistically, and psychometrically sound. The English version was independently translated into a Khmer version by two bilingual CHLs who are bilingual experts, familiar with the study content, as well as the everyday language, culture, and health behavior of CAs. Each translated version was compared and integrated into one version and this integrated Khmer version was finalized through a panel discussion. The translators commented during the panel that most of the questions were relevant because those questions pertain to a person's history and

**Table 2: Educational background**

1. What educational experiences have you had in the United States? Did you attend...			
a. English language school	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
b. Citizenship classes	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
c. Elementary school	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
d. Middle school	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
e. High school or ged	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
f. Technical or vocational school	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
g. College	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
h. Other	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
(Specify _____)			
2. Interviewer check: Did r live in a refugee camp?			
	<input type="checkbox"/>   <input type="checkbox"/> Yes		
	<input type="checkbox"/>   <input type="checkbox"/> No (Skip to B4)		
3. Did you receive any education in a refugee camp?			
	<input type="checkbox"/>   <input type="checkbox"/> Yes		
	<input type="checkbox"/>   <input type="checkbox"/> A little/some		
	<input type="checkbox"/>   <input type="checkbox"/> No		
4. Interviewer check: Did r live in cambodia?			
	<input type="checkbox"/>   <input type="checkbox"/> Yes		
	<input type="checkbox"/>   <input type="checkbox"/> No (Skip to 7)		
5. While you were in Cambodia, did you attend...			
Temple school?	<input type="checkbox"/>   <input type="checkbox"/> Yes	<input type="checkbox"/>   <input type="checkbox"/> No	
6. What was the highest level of school you attended in Cambodia? Did you attend...			
	<input type="checkbox"/>   <input type="checkbox"/> Attend elementary school		
	<input type="checkbox"/>   <input type="checkbox"/> Attend middle school		
	<input type="checkbox"/>   <input type="checkbox"/> Attend high school		
	<input type="checkbox"/>   <input type="checkbox"/> Have some college and/or higher		
	<input type="checkbox"/>   <input type="checkbox"/> Attended no school		

Table 3: HBV and liver cancer knowledge

1. Have you ever heard of Hepatitis B?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
2. Do you think that people can get Hepatitis B...	Yes	No	Don't know
a. Because it runs in the family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Through coughing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Through sex?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Through delivering a baby?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. By sharing spoons or bowls for food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. By sharing toothbrushes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. By being exposed to unclean medical instruments or needles?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Through drinking unclean water?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. By having salon manicures or tattoos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Is contagious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Now I have some more questions about Hepatitis B. Do you think...	Yes	No	Don't know
a. People with Hepatitis B get yellowish skin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. People with Hepatitis B get a swollen liver?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Hepatitis B can cause liver cancer in the long run?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Hepatitis B can cause liver hardening in the long run?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. For each of the following, tell me if you think the answer is yes or no, or say "don't know" if you feel you do not know the answer. Do you think that...	Yes	No	Don't know
a. Drinking too much alcohol can cause liver cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Smoking can cause liver cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Liver cancer is a matter of karma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Liver cancer is a matter of fate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Too much stress or hard life during Khmer Rouge or refugee camps can cause liver cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Table 4: HPV and cervical cancer knowledge

1. Have you ever heard of HPV?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
2. Do you think that...	Yes	No	Don't know
a. Women can get HPV because they do not have good personal hygiene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Women can get HPV through sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Women can get HPV by being exposed to an unclean woman exam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Women can get HPV through bad food eaten in the refugee camp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Women can get HPV because they were not able to keep clean during Khmer rouge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Women can get HPV because they were not able to keep clean in the refugee camp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Men can get HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Now I have some questions about cervical cancer. Do you think that... (READ A)	Yes	No	Don't know
a. HPV can cause cervical cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Women will get cervical cancer because it runs in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Khmer women are less likely to have cervical cancer than white women	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Smoking can cause cervical cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Cervical cancer is a matter of karma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Cervical cancer is a matter of fate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Most women with vaginal discharge or burning sensation worry about having cervical cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

that translating was not difficult or problematic for them. This integrated Khmer version was finalized through a panel discussion. The panel evaluated whether the translated Khmer version captured the meaning of the original English survey instrument, was grammatically and colloquially correct, and was written at a level of literacy or oral language appropriate for the CA mothers. The panel also reviewed the instrument for the purpose of ensuring psychometric soundness and cultural and linguistic sensitivity. The approach used by the research team has also

been used by the US Census Bureau where it was shown to be superior to the "translation and back-translation approach."<sup>[52,53]</sup>

#### Cognitive testing of the survey instrument (Stage 4)

Cognitive testing helps to determine whether the answer given by the respondent represents what the question was intended to elicit and to obtain information about the processes respondents use to answer the survey questions.<sup>[53-57]</sup> It is important to develop an interview

that can be consistently administered without interviewer improvisation. Our cognitive testing method used in-depth interviews through which interviewers sought to determine the respondent's ability to:

1. Comprehend what is being asked;
2. Retrieve information from memory;
3. Work with the information to put it in a form appropriate for answer; and
4. Provide response.

In addition, we asked whether respondents were able to read or comprehend the items when there were no Khmer words for specific Western medical terms.

The goal of cognitive testing is to evaluate how well each of these steps is performed and to enable the researcher to ascertain whether or not a question is working as intended and whether the information that respondents need to answer accurately is obtainable. The cognitive test was carried out in a series of several steps [Figure 1]. Researchers developed and provided cognitive interview protocols and offered general interview skills for standardized survey administration. For the recruitment of interviewers, the CHL recommended selecting interviewers who are of the same ethnicity, gender, and similar age group as the targeted group and actively involved in the Cambodian community. However, there were no staff who possessed both survey methodology expertise and Khmer language skills, so three bilingual, middle-aged (from 30s to 50s) CHLs who conducted individual interviews in Stage 1 were trained in standardized survey administration. The mode of training was a series of 2 day sessions in English between academic researchers and CHL data collectors. The CHLs shared their cultural, linguistic, and community

practitioner expertise. They advised the researchers on both what and how questions should be asked to respect to the cultural expectations of CA middle-aged women. The CHLs conducted mock interviews for at least two rounds using think-aloud and proving techniques. The questions included queries such as how the mother arrived at her answer about parenting on health education, what she thought certain terms meant, and requests to rephrase the question in her own words. Eight CA mothers participated in the cognitive interviews. All but one of the cognitive interviews were conducted in Khmer. After conducting the cognitive interviews, a debriefing session was held and any problems with comprehension or difficulty in formulating a response were noted by the interviewers.

For example, most participants responded, “have never heard of HBV or HPV.” The research team, therefore, discussed whether the participants who had selected this answer had elected to skip the subsequent knowledge questions because answering these questions would have contradicted their self-report. Two issues arose as a result of this concern; first, Cambodians perceived their answer of “have never heard of HBV or HPV” not in the literal sense but rather in the sense that they thought that they should have knowledge or direct or indirect experience with these topics. This is unlike native English speakers who feel they have the ability to make a judgment even if they do not necessarily know or understand the topic about which they are being asked. Furthermore, since there are no Khmer words for HBV and HPV, CA participants would be likely to skip the questions on HBV and HPV, which may lead CA participants to be excluded from data collection. Based on feedback from interviewers and CHLs, instead of excluding the participants who marked “have never heard” from answering subsequent knowledge questions, we decided to add an additional statement about the studied topic with a diagram as shown in Figure 2. CHL interviewers confirmed that participants in the cognitive interview interpreted the picture accurately.

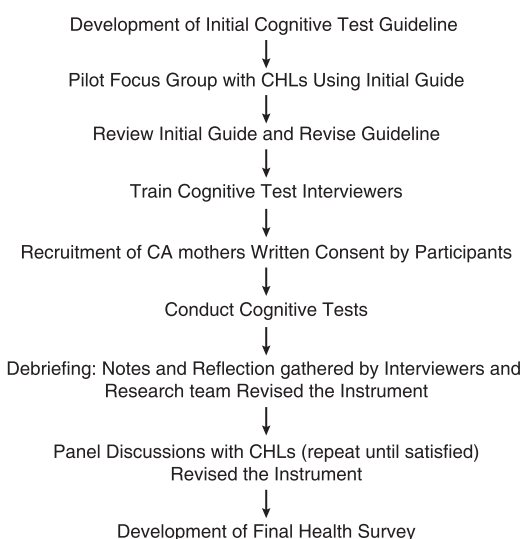


Figure 1: Cognitive test process diagram

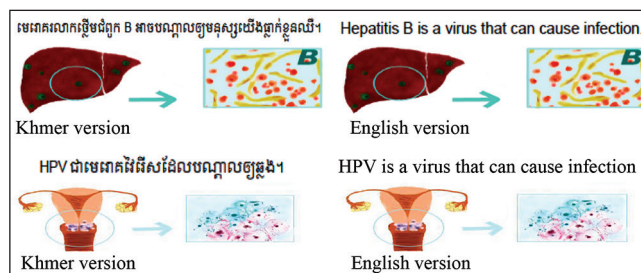


Figure 2: Visual Presentation of hepatitis B virus and human papilloma virus



## Discussion

This report describes the steps and processes involved in developing contextually relevant instruments. We first utilized focus group and individual interview data in both English and Khmer languages to explore, describe, and understand Khmer mothers' views, perceptions, values, and knowledge about HBV and HPV prevention for themselves and their daughters. These qualitative studies have allowed us to understand the process of experiential learning of CA mothers. Moreover, the historical and contextual information contained in the qualitative data enabled us to select culturally relevant items to measure categories of the constructs selected to study. Examining constructs from an emic perspective contributed substantially to our capacity to develop new measures and to provide guidance for future studies and interventions. The results of qualitative studies informed the construction of a structured and quantifiable survey instrument that was integrated with existing instruments derived from literature. In addition, results pointed to the fact that CA mothers had lexical problems related to the lack of Khmer words for health terms and resulted in using drawings as well as words. These sources informed our construction of a culturally appropriate quantitative instrument.

Using the cognitive interview approach to develop instruments has generated a body of methodological research and is a standard best practice in survey research.<sup>[54-60]</sup> Our team, however, encountered challenges conducting cognitive interviews with the understudied and underserved CA population. First, there is limited literature addressing cognitive testing among nonmainstream and non-English speaking AAPI populations until recently.<sup>[53,61]</sup> Nor is there literature on conducting cognitive interviews with CA mothers. Instrument development for our study — though time-consuming — breaks new ground with construction of new protocols [Figure 1] for each step from standardized interviewer training to debriefing of the cognitive test to ensure both psychometric properties and cultural and linguistic appropriateness. Second, the recruitment and training of qualified interviewers with the combined research and language skills challenged the assumed barrier of limited human and financial resources within the CA community. Third, through mainstream cognitive interview methods depend heavily on the verbal expressiveness and openness of the participants, CAs typically do not verbalize their inner their thought process. Finally, recruiting and training bilingual age-matched female CHLs was crucial to the successful implementation of the qualitative and cognitive interviews. These individuals were pivotal in identifying and recruiting targeted CA mothers, and

in assisting the participants to engage in the interview process. We were fortunate to have three highly skilled, knowledgeable, and committed CHLs who were respected members in their community.

To establish psychometric properties for this instrument, we carefully followed a standard procedure of instrument development.<sup>[48-52,62,63]</sup> Items were extracted from both qualitative data and exhaustive literature review and then selected by the content experts, including CA mothers, CHLs, and researchers. After identifying constructs to be studied, we selected words and phrases from Khmer native language based on qualitative data and panel discussions and then created a core set of items for the instrument. The researchers and CHLs assessed congruence between conceptualization and items and the representativeness of items on each construct. Cognitive testing provided formative validity through assessing item content, item styles, comprehensiveness, and responsiveness. Our Stage 5 full-scale quantitative study will further validate its psychometric properties.

The CBPR process facilitated the application and translation of abstract theoretical ideas of HBV and HPV prevention behavior by contextualizing and articulating culturally-relevant words and concepts for CAs. The early and intensive involvement of the community was a vital step in gaining the interest and trust needed for the instrument development with this targeted, under-served, under-researched population. The research process employed for this project provides a model for use in developing future surveys to aid health care professionals and researchers with other comparably targeted groups.

## Limitations

There are two major validity issues in the development of this instrument.<sup>[64,65]</sup> First, criterion validity requires an existing standard instrument be used as a criterion, but no such instrument exists. Second, even if there were a validated instrument in non-Cambodian culture, validity in one culture does not assure validity in another as we have learned in developing a number of new items. We anticipate utilizing the instrument to discriminate between experimental groups who receive health education and parenting on health education and a control group. Predictive validity can then be tested through future experimental studies. Also, since Southeast Asian Americans share similar socio-cultural contexts, cross-validation studies can be explored with other Southeast Asian American groups, such as Lao Americans, Hmong Americans, and perhaps Vietnamese Americans.



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