Development of Cervical Cancer Prevention Workshops for Hmong and Karenni Women Through a Community-Academic Partnership

Tana Chongsuwat, MD, MPH; Evan R. Decker, MPH; Molly Wilde, BA; Megan B. Fitzpatrick, MD; Mayhoua Moua

ABSTRACT

Background: In the United States, Southeast Asian immigrant and refugee women face many barriers to cervical cancer screening. This work describes and evaluates the use of community health workers and community-based participatory research in providing community-level interventions through a community-academic partnership to address these barriers.

Methods: Community advisory board members and mother–daughter dyads were recruited to help develop and refine cervical cancer educational materials.

Results: Feedback from 9 community advisory board members and 5 mother-daughter dyads identified areas for improvement to increase cultural sensitivity of materials and ensure the equity of voices during discussions.

Conclusions: Through this community-academic partnership, we developed cervical cancer prevention educational materials and workshops for Southeast Asian immigrant and refugee communities to serve as a resource to future cervical cancer screening programs.

BACKGROUND

Globally, cervical cancer is one of the most common female cancers for Asian women, likely due to barriers in access to health care services resulting in lower rates of vaccination and up-to-date screening compared to non-Hispanic White women.[1] Asian immigrant and refugee women in the United States face additional barriers to screening due to language, culturally discordant health beliefs, limited knowledge of host culture, modesty, fatalism, lack of access to health insurance, and social stigma due the association of HPV with sexually transmitted infection.[2,3]

Engaging community health workers (CHW) and community-academic partnerships are effective strategies to enhance health interventions for minoritized populations.[4-6] CHWs are typically representatives from the community and can serve as liaisons between community members and clinicians, promoting behavior change and increasing access to health services among ethnic minority women.[5] The use of community-based participatory research (CBPR) methods is essential in community-academic partnerships to ensure research is done in collaboration with those affected by the issue being studied, amplifying the relevance and authenticity of the knowledge created and the potential for positive change.[6]

Our project consisted of the development of a community–academic partnership between the research team at the University of Wisconsin School of Medicine and Public Health (SMPH) and the community organization Milwaukee Consortium for Hmong Health (MCHH). Our objective is to promote cervical cancer prevention by offering (1) educational materials co-designed and delivered by CHWs in the native language and cultural context of the participants and (2) community-level screening options, such as pap smears and human papillomavirus (HPV) testing, which can be clinician-collection or self-collected.

This study had 2 primary components: formation of a community advisory board (CAB) and development of mock cervical cancer educational workshops. In this paper, we discuss the process of developing the community-academic partnership and materials for cervical cancer educational workshops through feedback obtained from Hmong and Karenni CHWs and mother-daughter dyads.

• • •

Author Affiliations: University of Wisconsin School of Medicine and Public Health, Madison, Wisonsin (Chongsuwat, Decker, Fitzpatrick); Boston College, Boston, Massachusetts (Wilde); Milwaukee Consortium for Hmong Health, Inc, Milwaukee, Wisconsin (Moua).

Corresponding Author: Tana Chongsuwat, MD, MPH, 610 N Whitney Way, STE 200, Madison, WI 53705-2700; phone 224.260.1666; email chongsuwat@wisc.edu; ORCID ID 0000-0002-1129-0942

METHODS

The study was conducted over 9 months spanning 2021 and 2022. Two types of participants were recruited: members for the CAB and community members (as mother-daughter dyads) to attend mock workshops. Throughout the study, CAB members and the research team met 5 times virtually. Four mock workshops were conducted at MCHH's community center with mother-daughter dyads: the initial workshop for each ethnic group (Hmong and Karenni) presented the initial draft of educational materials developed by the CAB. Notes and feedback obtained from these first workshops were then presented to the CAB to guide revisions. Revised workshop materials were then delivered during the second workshop to each group. (See Table 1 for a timeline of the study activities.)

Table 1. Study Timeline and Activities

	Month of Study								
Activity	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Community advisory board meeting	X	X	X			X			
Mother-daughter mock workshop				Karenni dyads	Hmong dyads		Karenni dyads	Hmong dyads	
Workshop material development	Development of initial materials			Presentation of initial materials		Review/ Revisions	Presentation of revised materials		Review/ finalize

Table 2. Partnership Evaluation Survey Categories and Sample Questions

Category	Sample Questions
Communication	I feel like the research team communicates with me in a way that best meets my schedule and personal preferences.
Group Dynamics	I feel like the research team values my expertise by actively listening to my ideas.
Research Design	I feel like the research team considers the Southeast Asian community as a major role in guiding the project's direction.
Project Impact	I feel like the project uses the community resources efficiently.

Study approval was obtained from the Institutional Review Board at the University of Wisconsin School of Medicine and Public Health (Study ID# 2021-1003-CP002). Informed consent for both types of participants was obtained in English, Hmong, or Karenni, depending on participant preference.

Community Advisory Board

The community–academic partnership between SMPH's research team and MCHH began in 2020. Two CHWs – one Hmong and one Karenni – were selected by MCHH's leadership to work with the research team on the development of workshop materials and assist in recruitment, consent, and data collection for the mock workshops. The CAB members included these 2 CHWs, 5 members from the MCHH board of directors, and 3 community members of Karenni or Hmong ethnicity. Community members were selected by the MCHH leadership to assist in representing the community.

Prior to the first CAB meeting, the research team and MCHH leadership set project goals, expectations, and responsibilities for each organization and had discussions regarding potential for future initiatives and the partnership's ability to address disparities in the community through sustainable innovations.

The academic team and the CHWs collaborated to develop the workshop materials and then brought them to the CAB for review. They also selected a self-collection device for HPV screening to be offered in future workshops. The Evalyn Brush (Rovers Medical Devices B.V., Oss, the Netherlands) was selected based on efficacy and acceptability.[7] The manufacturer's instructions were adapted for a lower literacy level, translated, and diagrams enlarged for clarity. Due to varying levels of health literacy and English proficiency, materials used mixed-modality approaches presenting content (1) in posters and flip charts with minimal written language and using images of families with physical features like the target ethnicities, (2) in videos in the native language with English subtitles, and (3) with hands-on materials, such as anatomical models and equipment used during cervical cancer screening procedures.

The full CAB met in 5 virtual meetings covering various topics, such as the following:

a) the content, language, design, and delivery of educational materials
b) options for a self-collection screening device
c) feedback obtained from mother-daughter dyads attending mock workshops
d) the community-academic partnership and expectations
e) current and future collaborations

Iterative evaluation of the partnership was conducted through an anonymous online survey (Appendix A) after each CAB meeting. The survey was adapted and modified from toolkits and published CBPR methods.[8,9] Questions pertained to 4 categories: communication, group dynamics, research design, and impact (Table 2). Most questions included a 5-point Likert scale on level of agreement, and the survey concluded with 5 open-ended questions. Discussions during CAB meetings were recorded by a dedicated notetaker from the research team, and any written feedback obtained through email between CAB meetings was considered in the partnership evaluation.

A member from the research team independently analyzed the results 2 weeks following each CAB meeting. The summary results were then shared with the CAB team to open discussion for iterative adjustments to communication practices, CAB meeting structure, and the research design.

Mock Workshops

Mother-daughter dyads were recruited by CHWs and were assigned to either the Hmong or Karenni group depending on their self-identified ethnicity. We included mother-daughter dyads because older immigrant and refugee mothers often involve their daughters or other family members during health care visits to assist in translation and health decision- making.[10] The age for inclusion was 15 years and above for the young women ("daughters"). This age cutoff was determined by the CHWs as the most appropriate level of maturity for the educational topics.

Workshops were led by the CHWs, and mother-daughter dyads were expected to attend both sets of mock workshops. At least 1 member of the research team attended to observe, take notes, and provide any needed clarification on educational materials. Participants were informed that the materials developed by the CAB and research team were all work-in-progress and were encouraged to provide feedback on how the materials may be received by the Hmong or Karenni communities. CHWs presented educational materials mimicking the format of a real workshop, with feedback collected by CHWs throughout the workshop through semistructured questions (Table 3).

Table 3. Semistructured Questions for Mother-Daughter Dyads During Mock Workshops

Category	Sample Questions
Language	Are there any phrases or words in Karenni/Hmong which are… new to you? …do not make sense?
Self-collection	Do you feel like other members in the community would be receptive to the self-collection … method? …device?
	Do you think that members in the community would prefer this method over the traditional clinician-collection method?
	Are there any part of the instructions for the self-collection device which do not make sense or are confusing?
Comprehension	Is any of this information new to you?
	Is any of this information confusing?
	Do you feel like any information on cervical cancer prevention is missing?
Behavior change	Does any of this information encourage or discourage you from getting recommended cervical cancer screening?
Materials and delivery	What do you think about the delivery of the information? (ie, flip charts, hands-on models, video)
	Do you feel comfortable receiving this information from community health workers?
	Do you feel like having community health workers deliver this information provide more or less comfort to future participants?

RESULTS

Community Advisory Board

A total of 10 participants were recruited as CAB members. All participants self-identified as female, 6 identified as Hmong descent, 2 identified as Karenni descent, and 2 not of Asian descent. One Karenni community member withdrew from the project after the first CAB meeting, citing lack of time. At least 7 of the 10 members attended every meeting, and at least 5 participants completed the online survey after each meeting (Table 4).

Table 4. Community Advisory Board (CAB) Participation and Responses to Survey

CAB Meeting	Participants (n)	Survey Responses (n)
November 2021	10	10
January 2022	9	7
February 2022	8	6
April 2022	7	5
June 2022	7	5

All members responded positively to survey questions evaluating the partnership, and nearly 100% of responses were "strongly agree" or "somewhat agree" for all questions (complete responses to Likert questions included in Appendix B). The survey also evaluated CAB members' overall willingness to collaborate with the research team in the future, with the average response being 9.3 on a 10-point scale (1 = never want to collaborate again and 10 = will enthusiastically collaborate again).

Open-ended feedback received raised some concerns in each of the 4 categories. These included scheduling challenges, CAB members feeling uninformed of the full study design, concerns regarding dynamics of the panel inhibiting equity in voices and desire for members who were Hmong or Karenni to be more front and center. Within the CAB meetings, active feedback and iteration was valued, and changes included logistical considerations, such as using online polling for scheduling preference, promoting inclusivity by ensuring all CAB participants were provided information equitably, and summarizing key points via email for those who missed a meeting. To increase opportunity for feedback, any questions needing more reflection during meetings were sent via email to accommodate those not comfortable sharing among the group. Additionally, to capture discussion from each individual CAB member, a "round robin" approach was used after the third CAB meeting.[11] Examples of the feedback received and subsequent changes are provided in Table 5.

Mock Workshops

Three pairs of Karenni and 2 pairs of Hmong mother-daughter dyads participated in the mock workshops. A third Hmong pair was recruited but dropped out prior to the start of the study. Participants ages ranged from 17 to 48 years of age for Karenni participants and 15 to 43 years of age for Hmong participants. Dyads of the mock workshops (n=10) indicated that they liked the presentation and delivery of the materials and understood the content, with minor suggestions regarding language comprehension and suggested translation of words or phrases without a literal translation such as "handle," "pink," or "tampon." All

Table 5. Feedback on Partnership and Subsequent Changes Made

Category	Feedback and Quotes	Implemented Changes
Communication	• Overall preference for online polling approach to scheduling for flexibility. • In the first CAB meeting, members who were not involved in workshop development felt it was difficult to understand the scope of the project due to potentially missing information.	• Meeting dates and times scheduled through online polling. • A summary project scope was sent to all CAB members and dedicated time at subsequent meeting to provide a more thorough introduction to the project for those newer to the conversations.
Group dynamics	• "…I am working on being mindful of my own level of participation to allow for others to speak. I think the team would benefit from hearing from more [quieter] team members during the meetings…" • Suggest possible smaller breakout rooms if time allows.	• Allowed more space during meetings for discussion, invitation of each member to share thoughts through "round robin" approach, and those who may not feel comfortable in the larger group setting were encouraged to provide feedback through the survey, email, or one-on-one with CHWs or research team members.
Research design	• "….input – as a Caucasian cannot be front and center – and should not be made such."	• Weighed input from those that were of Southeast Asian descent of higher value as closer representatives of the community.
Impact	• "…I cannot judge whether or not it will lead to changes. It is too early for that to be known." • "…only hope that we will not have pushback from heads of family as this had been a past barrier and negatively impacted women's health options…"	• Discussed topics such as patriarchal decision making and other potential barriers in more detail with mother-daughter dyads attending mock workshops. • Determined it was difficult to determine impact based on survey questions and results therefore further evaluation of impact was saved for future directions.

Abbreviations: CAB, community advisory board; CHW, community health worker.

participants agreed that feedback provided during CAB meetings and initial mock workshops were incorporated adequately into the revised materials and were inclusive of and culturally sensitive to Southeast Asian families.

Self-collection was well-received as a potential alternative for cervical cancer screening in the future. Some participants had concerns that this method might be confusing or undesired by older women who may have difficulty with manual dexterity, although they were hopeful that this new initiative would provide better access for the community.

DISCUSSION

In this study, we developed a community-academic partnership between SMPH and MCHH focused on addressing barriers to cervical cancer screening among Southeast Asian immigrant and refugee women. Through this initial development phase, cervical cancer prevention workshops were able to be created for use in future implementation studies for the broader community. See examples of developed materials in Appendix C.

Community-based participatory research, which involves community members directly in all phases of project planning and execution, was a cornerstone of our approach. Through our close collaboration with leaders of MCHH, a trusted and respected community organization, we were able to engage with established community networks and incorporate cultural knowledge to better address the health needs of Hmong and Karenni women. The structure and content of our educational materials were informed by the knowledge gained in the culturally representative CAB. We adapted the structure of CAB meetings based on continuous feedback and iteration, ensuring that the voices and perspectives of all members were well represented. This collaboration enabled us to anticipate challenges that may arise during the next steps of conducting these prevention workshops or similar collaborations and adjust our methods accordingly.

It is important to acknowledge limitations in this study – primarily the limited sample size and design. Evaluation of community-academic partnerships typically requires an unbiased third party through in-depth discussions, which we were unable to incorporate. While we did modify the survey used in this study based on numerous validated sources and results were beneficial to the partnership, no definitive conclusions regarding strengths or weaknesses of the partnership between SMPH and MCHH could be determined. Additionally, as this partnership is in its infancy, it is difficult to assess the potential impact of the study, including factors such as reach, adoption, and maintenance of the workshops.

The materials developed for cervical cancer educational workshops will be provided to the broader community through the community-academic partnership with the goal of increasing cervical cancer education and screening among Southeast Asian immigrant and refugee women. Future initiatives should assess if knowledge attainment and behavior change due to the workshops (ie, obtaining cervical cancer screening, receiving the HPV vaccination, modifying risk factors) are successful.

CONCLUSIONS

This study provides an example of the use of community-academic partnerships to develop culturally tailored educational materials and workshops for cervical cancer prevention. The lessons learned from the partnership can serve as a resource for future collaborations by prioritizing community engagement, cultural relevance, and partnership, as we strive for more equitable health care interventions that effectively address disparities in underserved communities.

Funding/Support: Dr Chongsuwat was supported by the University of Wisconsin (UW) Department of Family Medicine and Community Health Primary Care Research Fellowship, funded by grant T32HP10010 from the Health Resources and Services Administration. This project was supported in part by grant 1UL1TR002373 to UW Institute for Clinical and Translational Research from the National Institutes of Health (NIH) National Center for Advancing Translational Sciences (NCATS). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Financial Disclosures: None declared.

REFERENCES

1. McDaniel CC, Hallam HH, Cadwallader T, Lee HY, Chou C. Persistent racial disparities in cervical cancer screening with Pap test. *Prev Med Rep*. 2021;24:101652. doi:10.1016/j.pmedr.2021.101652

2. Lor M, Khang PY, Xiong P, Moua KF, Lauver D. Understanding Hmong women's beliefs, feelings, norms, and external conditions about breast and cervical cancer screening. *Public Health Nurs*. 2013;30(5):420-428. doi:10.1111/phn.12043

3. Hawkins MM, Schmitt ME, Adebayo CT, et al. Promoting the health of refugee women: a scoping literature review incorporating the social ecological model. *Int J Equity Health*. 2021;20(1):45. doi:10.1186/s12939-021-01387-5

4. Braun KL, Thomas WL Jr, Domingo JL, et al. Reducing cancer screening disparities in Medicare beneficiaries through cancer patient navigation. *J Am Geriatr Soc*. 2015;63(2):365-370. doi:10.1111/jgs.13192

5. Kue J, Thorburn S, Keon KL. Research challenges and lessons learned from conducting community-based research with the Hmong community. *Health Promot Pract*. 2015;16(3):411-418. doi:10.1177/1524839914561515

6. Krishnan A, Tandon R, Nongkynrih B. Relevance of community-based participatory research in community medicine training. *Indian J Community Med*. 2020;45(3):256-260. doi:10.4103/ijcm.IJCM_343_19

7. Polman NJ, Ebisch RMF, Heideman DAM, et al. Performance of human papillomavirus testing on self-collected versus clinician-collected samples for the detection of cervical intraepithelial neoplasia of grade 2 or worse: a randomised, paired screen-positive, non-inferiority trial. *Lancet Oncol*. 2019;20(2):229-238. doi:10.1016/S1470-2045(18)30763-0

8. Joosten YA, Israel TL, Williams NA, et al. Community engagement studios: a structured approach to obtaining meaningful input from stakeholders to inform research. *Acad Med*. 2015;90(12):1646-1650. doi:10.1097/ACM.0000000000000794

9. Engage for Equity. Interview Guide for Self-Reflection and Evaluation of CBPR Partnerships: Version, 2017: Adapted from Research for Improved Health: A Study of Community-Academic Partnerships. Published 2017. Accessed March 28, 2023. https://engageforequity.org/tool_kit/focus-groups-and-interview-guides-for-partners/

10. Mosavel M, Genderson MW. Daughter-initiated cancer screening appeals to mothers. *J Cancer Educ*. 2016;31(4):767-775. doi:10.1007/s13187-015-0949-2

11. Round robin. BetterEvaluation. Published 2022. Accessed April 3, 2023. https://www.betterevaluation.org/methods-approaches/methods/round-robin

advancing the art & science of medicine in the midwest

WMJ

WMJ (ISSN 1098-1861) is published through a collaboration between The Medical College of Wisconsin and The University of Wisconsin School of Medicine and Public Health. The mission of *WMJ* is to provide an opportunity to publish original research, case reports, review articles, and essays about current medical and public health issues.

© 2024 Board of Regents of the University of Wisconsin System and The Medical College of Wisconsin, Inc.

Visit www.wmjonline.org to learn more.