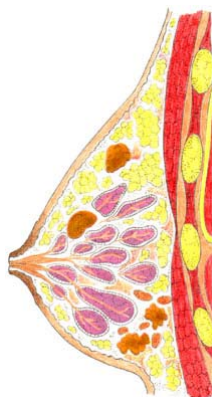# X-Plain Vietnamese Breast Cancer Tutorial Project
NNLM/PNR Outreach Project Award

K.K. Sherwood Library **and**
EthnoMed Website Program
Harborview Medical Center
Box 359902 325 Ninth Avenue Seattle, WA 98104-2499

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Submitted By:
Christine Wilson Owens
Box 359959 325 Ninth Avenue
Seattle, WA 98104-2499
Cpw2@u.washington.edu
Phone: 206-744-9091 Fax: 206-744-9967

X-Plain Vietnamese Breast Cancer Tutorial Project

1. Summary/Introduction:

The project successfully produced a new, quality resource of information about breast cancer for Vietnamese audiences. The resource is a multimedia, interactive tutorial that is accessible in several formats – web-based, CD ROM, and printed summary. The educational topics covered in the tutorial are: *Cancer and Its Causes, Breast Anatomy, Diagnosis, Staging, Additional Treatment,* and *After the Diagnosis*. For the online and CD ROM formats, each topic has a number of "screens" for a user to click through, with narration and visual text in Vietnamese language, illustrations and animated graphics, and option to view the text in English. The tutorial includes an introduction section explaining how to use the program, as well as True/False quizzes appearing periodically on screens throughout the program to test a user's understanding of the information presented.

The tutorial was developed with local community and clinician participation at Harborview Medical Center through the **EthnoMed** website program. The tutorial was produced with the *X-Plain* macromedia programming services of the **Patient Education Institute (PEI)**.

To learn more about EthnoMed, visit **http://www.ethnomed.org**
To learn more about the Patient Education Institute, visit
http://www.patient-education.com/

Outreach with the tutorial happened in multiple venues, including community centers, clinics, and professional meetings, reaching over 600 individuals throughout the project. It is likely that many more people have accessed the tutorial online, untracked.

The production of the *Vietnamese Breast Cancer Tutorial* attracted additional funding to EthnoMed from the National Cancer Institute and the Avon Foundation to develop several more cancer tutorials with the EthnoMed program. The *Cambodian Breast Cancer* and *Vietnamese and Cambodian Lung Cancer* tutorials have been produced also with PEI. *Vietnamese and Cambodian Colorectal Cancer* tutorials were produced in collaboration with a new partner, Health Way Software, using a different type of multimedia program and Web/CD/Print presentation. (See **http://healthyroadsmedia.org** and **http://healthwaysoftware.com**)

2. Geographic Region:

The project reached out to people in King County. The web-based tutorial likely has reached people in other counties via the Internet. EthnoMed presented or shared health education materials, including the multimedia tutorials, with regional and national audiences at conferences in Seattle, Washington D.C. and Sacramento, California.

3. Collaborations/Partnerships:

The Patient Education Institute (PEI)
The text and graphics for the *Vietnamese Breast Cancer* tutorial were modified from the source English version that was provided by the Patient Education Institute (the English version is licensed by the National Library of Medicine and can be viewed at:
http://www.nlm.nih.gov/medlineplus/tutorial.html.)
PEI provided the *X-Plain* macromedia programming services to the project.

The Patient Education Institute is "an established provider of patient and health education systems and software, serving hospitals, clinics, physician offices and related health care institutions. Since 1995, the Patient Education Institute has been developing evidence-based patient education systems and implementing them in healthcare settings. PEI's interactive patient education tutorials and systems provide health and safety education that is unbiased, up-to-date, and accessible to the widest possible segments of the population, in order to help people make informed health decisions that enhance their health and reduce medical errors."

Some of the challenges encountered in the partnership during this first tutorial project were rooted in learning the logistics of efficiently sharing the electronic components that make up the tutorial. Lessons were learned that informed a more cost- and time-efficient process. The production process involves both partners taking turns working on various components, such as text and narration, reviewing and incorporating new versions after gathering community and clinician input, and sharing large files over the Internet. The partners learned how to share the files appropriately and efficiently using a combination of zipping, attaching and posting the files for each other's download. EthnoMed learned to carefully order the steps in production and to group multiple requests for changes together, so as to eliminate too much back-and-forth editing work for PEI.

It was challenging for the non-Vietnamese speakers at EthnoMed and PEI to work with the Vietnamese narration files, and later even more so with the Khmer (Cambodian language) files. The issue was resolved by involving EthnoMed's bi-lingual partners in labeling and packaging the narration segments.

Handling language/fonts programs is a sensitive matter for a few reasons. Translators and reviewers may work with several different kinds of programs for a single language, and they are not always compatible with each other in that "back and forth" sort of way that an editing and reviewing process happens. Language and macromedia software programs interact in some peculiar ways with each other, too. The partners learned to troubleshoot problems occurring repeatedly with the language fonts displaying incorrectly with one or more specific characters altered or deleted throughout. Other than the persistent language issues, the technical aspects of sharing work was fairly smooth, with the usual challenge of navigating files across different computers and operating systems.

The Patient Education Institute programmers and project managers worked patiently and

creatively with EthnoMed, accommodating a learning curve with the first tutorial. PEI welcomed EthnoMed's suggestions for tailoring the tutorial, even taking certain suggestions into consideration for revising their own source material. For instance, they are considering adding a *Quitting Smoking* (i.e. prevention) section to their English Lung Cancer tutorial. The partnership between EthnoMed and PEI is being maintained with the new projects that have followed the production of the Vietnamese Breast Cancer tutorial.

Harborview Medical Center (HMC)
      Patient and Family Resource Center
      International Medicine Clinic
      Women's and Breast Clinic
      Community House Calls Program
      AANCART project at HMC

These programs and services at Harborview Medical Center offered natural points of partnership for this project. The Community House Calls program and AANCART project contributed staff members' bi-lingual assistance with translating and reviewing materials, facilitating outreach and community participation, and connecting the project with professional audiences at conferences and with lay audiences at community events. The Patient and Family Resource Center (PFRC), International Medicine Clinic and the Women's Breast Clinic provided outlets for the information to reach patients directly. Resource binders, with CDs and headphones were placed in each of these hospital locations, and staffs were oriented to the new materials and online version. In collaboration with the PFRC, a "prescription" card was created for providers to give to patients, encouraging them to visit the resource center to view/receive breast health information.

It is a challenge to call for the attention and interest of providers to take time out of busy hospital appointment schedules for directing their patients to a single and specific information resource. EthnoMed is hopeful and purposeful that as additional materials become available, the interest and attention among providers will increase. Certainly, their suggestions are being sought at meetings, most recently with the Ambulatory Care Clinics Leadership Team meeting, in October 2004. The bi-lingual project partners at Harborview, and the community audiences, expressed time and again their interest in having information available on more topics, in more languages. Physicians and staff in busy clinics may yet find better ways to use the materials with their patients.

Vietnamese Senior Association
The Vietnamese Senior Association (VSA) is a mutual assistance association serving 150 low-income seniors in Seattle. During this project the VSA facilitated community participation by recruiting individuals for translations work and focus groups, and by providing an outlet for presenting the completed tutorial to a large peer audience during the weekly senior lunch program. The partnership with VSA is ongoing for the production and dissemination of additional education materials. A challenge in this partnership, and in others, is to satisfy the desire and need for education materials on a variety of health topics. The X-Plain tutorials are very informative and detailed on specific topics, and are available in numerous topics in English and Spanish. But, the pickings are not very many for someone needing a Vietnamese language

multimedia tutorial on demand. To address the need for information, during outreach and presentations of the tutorial with VSA and other organizations, the project also distributed education materials about other health topics, in print and by pointing to sites on the Internet.

4. Training:

We used the outreach activity data collection form provided by the NNLM/PNR, found at **http://nnlm.gov/pnr/funding/toolkit.html** to a record of the events.

The total number of training sessions and exhibits conducted as part of the outreach project was 21. The total number of sessions in which half or more than half of participants were from minority populations was 14. The total number of participants in the project's sessions was 637, 453 who are health care or service providers and 184 members of the general public.

5. Training sites:

The emphasis of this project was the development of the tutorial and establishing good partnerships and processes for this work. The training and outreach included focus group discussions taking place during production of the tutorial, and community presentations with the completed tutorial and other resource materials.

Highpoint Tea Time Group: October 6, 2003
White Center Tea Time Group: February 14, 2004 and March 13, 2004
Both these groups are weekly gatherings of about a dozen or more women and men, primarily Vietnamese-speaking, living in low-income housing communities. These two groups were new partners with EthnoMed during this project. The groups provided natural meetings for field-testing and disseminating the education materials. Each group is located at community centers managed by Neighborhood House (NH), with NH staff on hand to support the groups with educational activities such as ours. Neighborhood House has a mission to help diverse communities of people with limited resources attain their goals for self-sufficiency, financial independence and community building, working in partnership with the Seattle and King County Housing Authorities and other social service agencies. The NH staff and community members welcomed our project's health education activities wholeheartedly. The staff received training in how to use the tutorial and assist community members in accessing it. The partnerships with these teatime groups continue as additional materials are developed and shared. Members of the communities at Highpoint and White Center have access to computers. The tutorial resource binder with CD and printouts, and an EthnoMed postcard with URL are placed near the computers to promote use. Headphones and speakers were distributed to the staff for use with the centers' computers, to encourage use of multimedia resources.

Refugee Women's Alliance (REWA): November 20, 2003 and February 12, 2004
The Refugee Women's Alliance is a nonprofit, multi-ethnic organization that promotes inclusion, independence, personal leadership and strong communities by providing refugee and immigrant women and families with culturally appropriate services. REWA advocates for social justice, public policy changes, and equal access to services while respecting cultural values and the right

to self-determination. Our training with the tutorial was conducted at REWA's main site at 4008 Martin Luther King Jr. Way S., Seattle, WA 98108, with 29 students in intermediate-level ESL classes. The training location was a computer lab/classroom with about 1 dozen new computers. The computer lab technician, 1 ESL teacher, and 3 staff persons working in community advocate positions were instructed how to use the tutorial with clients.

At REWA, the audience was mixed by language and country of origin, with immigrants from East Africa to Eastern Europe, Asia and Latin America. We showed the Vietnamese tutorial, and all present agreed it would be helpful to have the information available in their communities' languages. They were very attentive to see/listen to the Vietnamese tutorial, with English text displayed. For this group, it was necessary to have interpreters participate. Fortunately, REWA provided them.

Volunteers of America (VOA) Senior Lunch Program: July 16, 2004 and September 17, 2004
The Vietnamese Caseworker Cultural Mediator (CCM) from HMC's House Calls Program, along with several members of the Vietnamese Senior Association, arranged for the project to reach out to the Volunteers of America group on two occasions. The first activity involved around 70 seniors of various ethnicities, a mix of immigrants from countries in Eastern Europe and Asia, along with native-born American seniors. The group viewed the Vietnamese breast cancer tutorial, with the English text option, plus several of the Healthy Roads Media tutorials about topics Asthma, Cholesterol, High Blood Pressure and Diabetes. The group asked for printed copies of the information on these topics and others, including more cancer types. For the second meeting with about 50 members of the VOA group, copies of summary information from Healthy Roads Media and X-Plain programs were distributed on topics including Breast, Lung, Prostate and Colon Cancers, Eye Diseases, and Healthy Diet.

Helping Link: October 27, 2003
Yesler Terrace: October 13, 2003
The Program Director at Yesler Terrace Community Technology Center and the Executive Director of Helping Link Technology Center received training how to use the X-Plain tutorials (on EthnoMed and Medlinelplus). They received the tutorial binders, CDs and other printed health education materials to keep at the centers. The project gave headphones and speakers to the computer labs. Both Helping Link and Yesler Terrace are organizations with relatively high numbers of Vietnamese immigrant patrons who use their facilities. Both leaders welcome announcements of new health information from EthnoMed.

Harborview Medical Center: Ongoing "In-reach"
Meetings with Ambulatory Care Services department committees and clinic personnel were good opportunities and points of accessibility to share this tutorial and other EthnoMed projects with people in roles of administration and delivery of patient care services at Harborview. HMC groups we "marketed" the tutorial to during this project included: Primary Care Clinics' Patient Care Coordinators, Primary Care Clinics' Medical Directors, Breast Care Clinic Nurse Manager, Rehabilitation Clinic Staff, and Nurse Practice Committee. In all, sixty-one professional staff and faculty at Harborview received instruction in the availability, accessibility and example of the Vietnamese Breast Cancer Tutorial, and other multimedia education. Additionally, HMC's

Patient and Family Resource Center (PFRC) staff members continue to publicize the tutorials as appropriate to the information needs of their visitors.

6. Exhibits:

In the first few quarterly reports, the Exhibit Report Outline was used to record the outreach we were doing. In the later quarters, we used the Outreach Activity Data Collection Form instead, as it seemed a better fit for capturing the participant data and for describing the training activities. The tutorial was exhibited, along with other health education materials, at the following events:

The 2nd Annual Vietnamese Health Fair, Seattle, WA happened on July 19, 2003 and Christine Wilson, Hue Thai, Kim Lundgreen, Ann Marchand, Carey Jackson, MD staffed the HMC health information table. The people visiting the booth to view the tutorial and other education numbered 40 and included young Vietnamese health professionals and lay community members. The number of NLM System Demonstrations was 4. HMC's was one of 20 tables set up along the short periphery of an elementary school gym. The tutorial was displayed on the wall behind our information table, and a chair was set up for people to take turns using the mouse and keyboard to view module topics in consecutive order, or to skip around to different topics. Four people, 3 women and 1 man viewed the tutorial in its entirety. About 40 other people viewed portions of the tutorial. Visitors to the table received ethnomed.org pens and medlineplus.gov bookmarks. This event was great to connect with the professionals, though was a small venue for reaching very many community members directly, in its 2nd annual organization.

The International District Health Fair happened in Seattle, WA, on King Street, in Chinatown, Saturday July 12 and Sunday July 13, 2003. Christine Wilson Owens, Hue C. Thai, Ann Marchand, Paularita Seng, and Dr. Carey Jackson staffed the HMC health information table at the event. The number of people visiting the booth for the tutorial exhibit was 20 each day, for 4 NLM System Demonstrations. One hundred people visited the booth each day. Though this fair is as festive as it is informational, it is still a very good visibility point in the community, reaching multiple language and ethnic groups. Give away items work well at this fair! URLs and brief text message printed on pens fly like hotcakes, into the homes of families! Families may be linguistically, culturally, and technologically diverse within generations so it is hopeful that the pens, handouts and bookmarks given away will lead some of them to quality health information when it's needed, or to places where they can get help to find it.

Washington State Breast and Cervical Health Partner Training Institute and the 5th Annual AANCART Academy were two of the regional and national conferences at which EthnoMed and other online resources of health information were promoted and/or demonstrated.

The Washington State Breast and Cervical Health Partner Training Institute was held October 8, 2004 at Fred Hutchinson Cancer Research Center, reaching an estimated 150-200 people working as breast and cervical health care providers, patient advocates, researchers and

educators in Washington State. EthnoMed staff participated in a panel presentation about "How to Find Culturally Appropriate, Inexpensive and Accurate Materials" focusing on Web-based and Multimedia materials. A 5-page handout was distributed listing several dozen websites, reviewed as quality health information sources by libraries and/or government groups. This particular handout is well-received by many audiences who remark that they have desired to know where to go for information and the handout helps them do this strategically. The way the handout is organized highlights websites that are good places to start looking for information on specific topics and in particular languages.

The national Asian American Network for Cancer Awareness Research and Training (AANCART) has 5 sites, one of which is located in Seattle as a collaboration between Fred Hutch Cancer Research Center and Harborview UW Department of Medicine researchers and clinicians, with the Cambodian and Vietnamese communities primarily, and also with Chinese communities. **The 5th Annual AANCART Academy** held October 21-23, 2004, gathered together individuals representing numerous diverse backgrounds with an interest in and dedication to cancer prevention and control in Asian and Pacific Islander communities. Representatives from community-based organizations, private businesses, the medical and research community, public health, and others came together to celebrate what AANCART has accomplished to date and what to look forward to in the next five years. This academy was hosted by the Sacramento Region of AANCART, and highlighted presentations by the Director of the National Cancer Institute, Dr. Andrew von Eschenbach, and the President of the American Cancer Society, Dr. Ralph Vance. During a conference workshop session about the Seattle AANCART program, EthnoMed was mentioned as a source of information for communities, offering some new multimedia technology to help reach across literacy boundaries.

A component of Seattle AANCART's recent proposal to NCI for second-round, 5-year funding involves EthnoMed broadening to be an information resource serving additional language communities through the national AANCART network.   Inclusion of EthnoMed for consideration in a new AANCART contract through NCI's Special Populations Network is a vote of confidence and validation for the project and further support of continued growth and awareness of the resource. AANCART, along with another "exhibitor" at NIH - NLM's Medlineplus website with links to the multilingual tutorials – is an emerging network available to us for distributing health information to our target audiences.

Additional outlets used for publicizing and demonstrating the multimedia materials during the timeframe of this project were a presentation made at the Annie E. Casey Foundation conference in Washington, D.C. and reports made to the Avon Foundation Program at Harborview.

7. Resource materials:

Resource binders were created containing bi-lingual (English and Vietnamese) instructions and feedback forms for users, color-printed summaries of the educational content, and CD ROM. Additional materials were also included in the binder, such as a 6-page resource list written in Vietnamese of local organizations that provide health and social services in Seattle King-County, and a colorful Health Promotion/Preventing Cancer poster with text in English and Vietnamese. Headphones and small computer speakers were distributed along with the binders.

A main page for the Vietnamese Breast Cancer tutorial was created:
http://www.ethnomed.org/ethnomed/patient_ed/cancer/breast_cancer/breast_cancer/xplain.html

This page is linked from EthnoMed's homepage: **http://www.ethnomed.org/** and it is linked from the Breast Cancer page on the National Library of Medicine's Medlineplus website: **http://www.nlm.nih.gov/medlineplus/breastcancer.html** under the section "Other Languages."

The NTCC Educational Clearing House will be contacted when all the additional tutorials have been completed and posted. In the last month, the Cambodian Breast Cancer and Vietnamese Lung Cancer tutorials have been posted to:
http://ethnomed.org/patient_ed/cancer/xplain/CambodianBreastCancer/xplain.html
http://ethnomed.org/patient_ed/lung/VietnameseLungCancer/xplain.html

We expect to post the Colorectal Cancer tutorials in English, Khmer/Cambodian and Vietnamese languages on EthnoMed by the first of the New Year. Currently, the files can be viewed at:
http://www.healthyroadsmedia.org/

8. Web sites:

The EthnoMed web pages listed above were created as part of this project. The EthnoMed Webmaster controls the ongoing maintenance of these pages and is well supported by the University of Washington Health Sciences Library staff and server. The tutorials will also be placed on the Patient Education Institute's server and are available to the National Library of Medicine's Medlineplus website team for placement on their server as well. Currently, Medlineplus links to EthnoMed's tutorial pages. Prior to this project, user numbers for the EthnoMed website and visits to specific pages were tracked. Monthly site visits averaged 70,000. During the time period of this project, however, there has been no tracking system in place, making the impact of the project among internet-audiences hard to measure or quantify.

9. Document delivery and reference services:

Document delivery and reference services were not applicable to this project.

10. Approaches and interventions used:

Delivering the education happened via presentations made to community organizations, clinic staff, and professional audiences at conferences and meetings, via distribution of the resource binders, and via the EthnoMed and Medlineplus Web pages.

Producing the multimedia tutorials involves detail-oriented steps and collaborative work among many people. For this project, the paid and volunteer personnel consisted of community translators and reviewers, Harborview clinical and bi-lingual staff, and organizations' staff. The participants were coordinated through the Refugee and Immigrant Health Promotion Program

offices where AANCART and EthnoMed projects dwell at Harborview, close to the House Calls Program and Interpreter Services Department offices. Persistent and careful attention by several pairs of eyes maintained accurate and appropriate health education messages throughout the process. The main process difference between the production of PEI/*X-Plain* materials and the Health Way Software/Healthy Roads Media materials is that the former starts with PEI's content from a completed English tutorial, whereas the latter starts from scratch to develop basic educational content for both an original English and another language(s) tutorial(s). Regardless of which multimedia program and collaborator is involved, the production process involves numerous back-and-forth editing sessions per tutorial, gathering community input as the content develops. An overview of this process is described below:

➢ Source materials:
Educational materials are developed/identified in English. Primary care physicians and oncologist advisors are engaged in creating new/revised content. The English source materials are reviewed and approved by the caseworker cultural mediators (CCMs) and/or interpreters from the target language population prior to translation. Any major changes are clarified with the advising doctors.

➢ Translations:
The translation process conforms to World Health Organization (WHO) standards. Two translations are independently produced for each document. These translations are then reconciled and a final translation agreed upon by a team of experienced translation reviewers.

➢ Multimedia Programming:
The translated text is incorporated into the multimedia program. EthnoMed staff and/or the programmers select initial draft images. Cross-cultural mediators and interpreters troubleshoot font problems, through discussions with the programmers, to make certain that the text appears correctly onscreen.

➢ Focus Groups/Community Participation:
At least 2 focus groups are held for community members to review the draft multimedia programs to solicit feedback on clarity and cultural appropriateness. The programs are modified based on feedback. All changes are further reviewed and approved by the participating physicians to assure medical accuracy throughout the materials.

➢ Multimedia Programming:
Narrations are recorded and audio components added to the multimedia programs. Printable handouts are reviewed and formatted by the caseworker cultural mediators (CCMs), interpreters or community translator. Cross-cultural mediators, interpreters and/or community liaisons conduct final reviews to assure that translations are accurate and culturally appropriate.

➢ Web Publishing:
The final products are placed on the EthnoMed website. The Patient Education Institute, Health Way Software and Medlineplus may also place educational materials and tutorials on their websites. Educational packets, including resource binders with print materials, CD-ROMS, and instructions for use are produced and distributed throughout EthnoMed's network of

partnering community organizations and technology centers in Seattle, at Harborview Medical Center clinics and patient and family resource center.

> ➢ Outreach

Sometimes with and sometimes without the assistance of bi-lingual caseworkers/educators in Harborview's House Calls Program and AANCART project, local community organizations are called directly to schedule outreach sessions. Contacts are already well established with some of these organizations during previous EthnoMed, AANCART and House Calls work. Bi-lingual staff at the community organizations developed and posted flyers to promote the sessions, or they used word of mouth to share the event information with their clientele.

11. Evaluation:

The project goals were:

> ➢ To develop a Vietnamese language X-Plain Breast Cancer Tutorial to share with Vietnamese patients and community members.

> ➢ To develop a working relationship between EthnoMed and the Patient Education Institute (PEI) for completion of the tutorial and to establish possibilities for future collaboration.

> ➢ To continue to grow the relationship between EthnoMed and the NN/LM for community educational outreach and to continue to foster the relationship between the Vietnamese community members and EthnoMed.

These goals were achieved. Across all community training sessions, and most professional meetings, the verbal feedback was immediate and repeated:

"Thank you so much for making this for us!"

"What other topics do you have?"

"When can you come back and show us more?"

"I/my clients like the pictures and the listening (narration). I don't have to read all the information."

"Where can I find this later?"

Each time we presented the tutorial to a group of community member who were mostly low-income community members, speaking English as a second language, it was clear that few of them would be accessing the information on the computers without having help from an intermediary person – like a staff member at a computer lab/community center or a family member with computer skills. The interface of the education requires a user to have some

English language skills, and some basic computer navigation skills. For now, at least, that does limit the direct use of the resource by people in our target audience who may need it most. The tutorial and other online information, when presented to large groups and via individuals who are already in mediator/advocate-type roles in the communities, proves to be well accepted in this project. The question remains what approach, or combination of approaches, can make the information more accessible for our target audience(s).

The feedback about the tutorial's design and functionality was given during the production process, in focus groups, at demonstrations, and by the true/false quizzes and user survey. As a rule, there was a sense of our audiences "gobbling up" the information we shared with them in this project, clarifying the messages about breast cancer, and looking ahead to other topics.

For computer-literate audiences, hands-on navigating the tutorial program was not a problem, as seen in the responses collected via user feedback forms.

The most astoundingly successful results achieved, based on the objectives of the project, were the new and the renewed partnerships and funding which followed immediately after the completion of the scope of work for this first tutorial.

12. Problems or barriers encountered:

The most constant problem is monitoring the true use of the tutorial. Changing faces and busy schedules of patient care services at Harborview clinics pose challenges for building awareness of the information resources among providers.

An unknown number of people have accessed the online tutorial and in the future it is a good idea to try and track users. It may help to evaluate the resource further with an online survey, as is used right now on Healthyroadsmedia.org.

Minor equipment/telecommunications issues came up at a handful of meetings, mostly challenges easily-overcome.

PEI is still working to make the auto-run CD function active, a still lingering shot of trouble with the latest tutorials.

There are questions still for how best to balance the delivery of a specific tutorial, targeting a single language or ethnic community, and also responding to requests for health information on multiple topics, in multiple languages, in multiple communities.

 No barrier, other than a learning curve, was encountered in attaining and maintaining the UW Human Subjects' "Exempt Status" for the project.

13. Continuation plans:

EthnoMed has recently proposed a new scope of work for the next 2 years in partnership with the Avon Foundation, and in collaboration with other supporters like AANCART. The work would include the production of:

➤ Breast Cancer Tutorials in 3 languages (possibilities: Tagalog, Korean, Chinese-Cantonese, Somali, Amharic);
➤ Breast Cancer Survivor Audio Testimonials in 2-3 languages (possibilities: Vietnamese, Khmer, Somali, Amharic);
➤ Multimedia Education Modules in at least 2 languages about Types of Chemotherapy, and about Clinical Trials – What are they? What are the benefits?

From a proposal recently submitted to Avon:

"The new scope of work would also include the exploration of ways to direct more users to EthnoMed and to leverage resources for sustainability. Toward those ends, we may advertise in journals, initiate collaborations with groups like the Bureau of Primary Care, the Kaiser Foundation, the National Association of Public Hospitals and AAPCHO, and submit funding applications to such a group as the California Endowment.

"Continuing to expand the reach and sustainability of EthnoMed has been an important goal of the EthnoMed development team. As part of the new scope of work, EthnoMed staff will engage groups like the Bureau of Primary Care, the Kaiser Foundation, and the National Association of Public Hospitals in discussions about how they might be of assistance in disseminating EthnoMed resources to their respective constituencies.

"Members of the EthnoMed team have been invited to be founding members of the National Coalition for Quality Translations in Health Care being formed by Kaiser Permanente's National Linguistic and Cultural Programs of National Diversity. Carey Jackson, clinical director of EthnoMed, will sit on the Advisory Board for this national coalition and will have the opportunity to provide the other coalition members with updates of the new and existing EthnoMed materials.

"Similarly, Dr. Jackson has been invited by The Center for Health Professions to be a member of the steering committee for "LEAD-ing Organizational Change: Advancing Quality through Culturally Responsive Care". This program resides at the University of California, San Francisco, in partnership with the California Association of Public Hospitals and Health Systems (CAPH) and its education and research affiliate, California Healthcare Safety Net Institute. The program is comprised of four change strategies, LEAD: Leadership, Education, Accountability and Dissemination toward integrating culturally and linguistically competent care into California's public hospitals and health systems. Being a member of the steering committee for this program will allow EthnoMed the opportunity to become a relevant tool for some of California's Safety Net institutions and to promote patient educational materials."

14. Impact:

The "library" is always spoken about at every meeting, event, outreach activity or focus group during EthnoMed community projects. The "library" at times can mean one or more entities: KK Sherwood Library, the Health (Sciences) Library at the UW, and the National (Networks) of Libraries of Medicine (NLM and NNLM). The community members hear "library" and know it is a place for finding information, including health information. The actual impact, based on word of mouth reports, is that Ethnomed.org and Medlineplus.gov are becoming recognizable in communities as sources of health information.

15. Recommendations for improvement:

New designs are being crafted for the newest X-Plain tutorials, including adding "co-branding" Logos to identify the materials more clearly with EthnoMed and AANCART, making CDs and resource binders with combination files organized by languages and topics, and updating the user instructions handout.

The 2 types of multimedia programs being produced could be evaluated in focus group discussions comparing and contrasting the educational formats, by using more pre and post tests to measure "readability" or "listen-ability or "visual-ability" constructs, like animated illustrated graphics vs. mostly photographs; readability and appropriate health literacy levels of similarly themed/topic-ed text; "auto-run/movie format" vs. "clicked-through- by- user" interactions.

We should do more to combine efforts with groups, where they exist, in teaching basic computer education to target communities, both to introduce the education and further evaluate user-friendliness through hands-on, participatory exercise. The bi-lingual, mediated, presentation-type encounter described in this report as the primary mode of outreach could be examined alongside a hands-on approach of delivering the education.

Training EthnoMed staff and bi-lingual partners to program multimedia materials themselves, in addition to working with contracted collaborators like PEI and Health Way Software, may be an idea for the future, as a cost-saving and skills-building investment over time. Should the demand for these materials grow, there is potential to tap the talent and expertise in our local communities. Rather than always starting with English, work could be done to develop new materials initially and directly in the language of the target audience. This approach was considered in a thesis investigation by a recent UW MPH graduate who evaluated it as favorable compared to other approaches, as an attractive alternative to translation, for producing culturally and linguistically appropriate education materials.

16. FOLLOW-UP QUESTIONS

1.   The original project goals and objectives were met well.

2.   Please see above section "Approaches and Interventions Used" for specific steps that would be of interest or use to others conducting outreach projects. The strategies most effective in implementing the project were to build on natural connections among related projects and to work with people highly qualified in language access and health education

arenas.

3.   If we were to start all over again, we would first produce a tutorial in the target language called "Cancer 101", which currently exists as a PowerPoint Presentation developed by the Hawaii AANCART site as a template that adjusts for various communities. Timing doesn't always work that way, so the cart before the horse it goes…

If we could go back, we may decide to plan a full project for development and evaluation of the material, and a second full project for outreach, for better focus on each of these stages.

4.   The advice or recommendations I would give to anyone considering a similar outreach effort would be to have a good filing system in place at start of project to keep track of details related to the written and audio language, and design for each component of the tutorial(s). Very quickly at each step in the process, the details can pile up on sticky notes and reviewed drafts, followed by occasions of catch-up sorting out and filing, in efforts not to overlook small or large modifications, in between missing accent characters and sometimes-confusing True/False quiz constructions.

The other advice I would give is to confidently trust the NNLM/PNR to support the project wholeheartedly with consistent and helpful administration of the grant.

Thank you!
Cám ơn!
(We are grateful in English and in Vietnamese ☺)