

Culturally and Linguistically Appropriate Health Education Materials: Access, Networks, and Initiatives for the Future

An Exploration

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Introduction

Health disparities in the United States correlating with race, ethnicity, language, economic status and other demographic factors have been documented by numerous researchers. According to the CDC, populations experiencing health disparities are growing as U.S. demographics change. The future of American health depends on understanding, addressing, reducing, and eliminating these disparities. Disparities have been documented in infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS, immunization rates, asthma, environmental health risks, health literacy, life expectancy, insurance coverage, and just about every other major health issue.^{1, 2}

In 2006, four bills addressing health disparities, sponsored by Senator Rosa Franklin, D-Tacoma, were signed into law by Washington State Governor Christine Gregoire.³ Senate bills 6193 requires surveys of health professions work force supply and demographics; 6194 is intended to increase health professionals' cultural competence by requiring that health profession education programs include curricula addressing the topic by 2008; 6196 requires that the Washington State Board of Health include a health official from a federally recognized tribe; and 6197 created the Governor's Interagency Coordinating Council on Health Disparities.⁴

In response to this legislation the Board of Health requested proposals for assessments of the state of language access to health care in Washington, addressing either interpreter services, culturally and linguistically appropriate health information, or both. The Cross Cultural Health Care Program received a contract to explore and assess the latter, culturally and linguistically appropriate health information, and possible mechanisms to improve access to such materials. In late 2006, CHOICE Regional Health Network published two policy reports addressing medical interpreter services in Washington and recommending options for improvement: *Quality Assurance Options for Health Care Interpreting in Washington State* (October 2006) and *Quality Assurance Approaches for Health Care Interpreting: Nationwide and Washington State* (August 2006), available at <http://www.crhn.org/tusalud/>. Their work included assessing the quality of

¹ Centers for Disease Control and Prevention. "Eliminating racial & ethnic health disparities." Atlanta: CDC, 2007. <http://www.cdc.gov/omh/AboutUs/disparities.htm>

² American Public Health Association. Health disparities factsheets. In *Eliminating health disparities: Communities moving from statistics to solutions – Toolkit*. APHA, 2004. <http://www.apha.org/advocacy/priorities/issues/disparities/legislativehealthfact.htm>
<http://www.apha.org/advocacy/priorities/issues/disparities/legislativehealthfact.htm>

³ Office of Senator Rosa Franklin. "Governor signs package of bills addressing health care disparities." From Rosa Franklin's web site. March 27, 2006. <http://sdc.leg.wa.gov/2006/Releases/Franklin/2006/disparity.htm>

⁴ For more information on the Health Disparities Council, see Governor's Interagency Council on Health Disparities: Strategic Action Plan to eliminate health disparities – Draft work plan. Olympia: The Council, 2006. http://www.sboh.wa.gov/hdcouncil/Meetings/2006/2006-12_05/Documents/Tab06a-DraftWorkPlan.pdf

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some of the health materials commonly used by clinics in southwest Washington. These reports, products of extensive effort and expertise, present information that might fill the Board of Health's needs in this area concerning interpreter services, and CCHCP sees no need to repeat their effort. CHOICE plans to build on this work and CCHCP may be interested in collaborating with them.

Culturally and Linguistically Appropriate Health Information

A vast proliferation of information is currently being produced in attempts to improve patient education and access to care in underserved communities. Health educators, providers, and institutions produce materials in various print, audio and video formats, in common and lesser-known languages of immigrants, refugees and ethnic minority communities. Information tailored to African Americans, indigenous tribes, LGBT communities, people with limited literacy, and other distinctive populations is becoming easier to find. Books, DVDs, websites, and articles attempt from various perspectives to improve health professionals' cultural competence and enable them to better serve patients of backgrounds other than their own. Quality runs the gamut from excellent to embarrassing. Much information is buried deep in little-known web sites.

In the context of this report, "culturally and linguistically appropriate health information" refers to materials and programs for both providers and patients. Common examples could be profiles of local communities geared toward health providers, intended to improve care to the community in question; cultural competence assessment tools; and patient education and health promotion materials developed specifically for a community using that community's language and informed by its culture.

The sheer enormity of this output puts a complete assessment and listing of existing materials out of the scope of this project and is quite likely impossible. In this age of broad internet access, to address only information produced in Washington State would assume an artificial boundary. Information sought and used by patients and providers may prove to be from another state, county, city, or country; may be commercially produced or in the public domain; or may originate with non-governmental organizations operating anywhere in the world.

Instead, this report will describe some of the notable sources and organizers of culturally and linguistically appropriate information locally and nationally, discuss related cultural competence issues, and look into some possible ways to increase access to such materials through building on existing infrastructures. The centerpiece of this project was a focus group and interviews with professionals particularly interested in linguistic access to care, cultural competence, and access to information. The focus group and interview report serves as the project's main discussion, with the author's interpretations and ideas integrated into the section. At the end of the focus group section the report pulls together some common themes and ideas toward improving access to culturally and linguistically appropriate health information. A condensed version of the interview and focus group notes comprises an appendix at the report's end.

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During the focus group and interviews, participants aired many ideas and referenced numerous organizations and projects whose efforts towards culturally competent information and services they highly regard. These and other resources' current and potential roles are further explained and elaborated upon in the Resources for Culturally and Linguistically Appropriate Health Information section. The Resources section is not meant to be a comprehensive directory, but as a report section to be read in order to learn about current resources and their potential.

Focus group and interviews: Culturally and linguistically appropriate health information – Ideas and issues

A total of nine individuals participated in either a focus group or individual interview. Both settings utilized the same questions. All participants are involved in work that aims to improve access to care for underserved communities, such as interpreter services, training of service providers, community outreach, and culturally and linguistically appropriate health promotion/patient education materials. The following section is not a straight-up report of the focus group and interview data; instead, it integrates ideas and discussion from the author with the data. See the appendices for the unadorned focus group and interview data if it isn't completely certain whether an idea came from participants or the author.

Note: In the following text regarding focus group and interview outcomes, "I" refers to the speaker or participant, not the present author.

1. Please introduce yourself and give a brief synopsis of your work as related to culturally and linguistically appropriate health information.

- Health educator with CHILD Profile (Washington State Department of Health), which produces multilingual immunization information and tracks Washington kids through age 6 in an effort to ensure consistent immunization.
- Training manager with Minority Executive Directors Coalition. Facilitates cultural competency and anti-racism training for other organizations. Formerly health educator and program manager with Cross Cultural Health Care Program's Health and Nutrition Demonstration Project which developed culturally and linguistically appropriate programming for people with or at risk for chronic conditions such as obesity, diabetes, hypertension and heart disease, in the Pacific Islander, American Indian and Alaska Native, Filipino, Hmong and Mien communities.
- Academic health librarian, liaison to UW Medical Center. Assesses providers' needs for patient education material and cultural information for themselves. Contributor to UW Medical Center's *Culture Clues* ethnic community profiles, which utilized collaboration with cultural informants; end-of-life profiles are under development with three now complete.

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- Health educator in health promotion at Washington State Department of Health, administrator of H.E.R.E. database of Washington programs and materials in health promotion. Monitors quality of materials and programs. H.E.R.E.'s resources include a repository of documents in non-English languages. The program is funded and the site is currently being overhauled.
- National Network of Libraries of Medicine Pacific Northwest Region Outreach Coordinator. Performs little direct work with culturally and linguistically appropriate health information except for some passed-along reference questions. As Outreach Coordinator, helps approve and distribute funds to health information outreach projects around the northwest.
- Interpreter services manager for Swedish Hospital in Seattle. Serves on patients and physicians committees. Experience in process control, optimizing efficiency.
- Librarian, Health Education Coordinator, National Network of Libraries of Medicine Pacific Northwest Region. Role includes working with intermediaries from underserved communities to disseminate health information.
- Librarian, Harborview Medical Center and creator and manager of Ethnomed.org, which produces and posts culturally and linguistically appropriate health information for providers and patients.
- Librarian at Public Health – Seattle & King County; position includes managing digital public health library; was passed a long-time Public Health project that collects and evaluates health promotion materials. The collection is now on the H.E.R.E. database at the State Department of Health. Public Health is not currently reviewing materials for that collection.

2. Please describe the ideal information system for culturally and linguistically appropriate health information. What qualities should it have?

User friendliness and accessibility:

Participants wanted a system to be as simple and convenient to use as possible. It should take little or no more effort to use than any of the other “instant”–electronic services we have come to expect in our lives, such as on-demand viewing and podcasts. They’d like it to be Internet based, on providers’ desktops, and available where people spend time from day to day such as barbershops, faith communities, community centers, workplaces and homes. Participants also expressed concern about overlapping and redundancy.

Cultural competency:

Developing culturally and linguistically appropriate information and services:

Tools and information should be developed based on a particular community’s needs, not according to outsiders’ or public health workers’ assumptions about what that community needs. What the audience needs is not necessarily what a public health worker thinks it needs. Tools and information should take into account varying literacy levels and learning styles and not be limited by the linear approaches of Western

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medicine. People developing resources should be prepared to work with these differences. Participants stressed that materials should be developed for an audience rather than just translating pre-existing information. One participant spoke of the long process of developing trust, relationships, and understanding with a target community, and that no two programs can or should be alike. Maximum usability will require much flexibility. Medicine has its own unfamiliar language that stymies even English-speaking audiences. Also, target audience should be expanded to include families and other caregivers, since someone else in the family may be the one able to utilize a resource, and the whole family may be involved in decision-making and care. One shouldn't assume that because the patient is LEP or unfamiliar with technology that no one in the family will be able to put it to use for the patient's benefit.

Community buy-in and review is vitally important to developing culturally appropriate resources that will work for and be used by the respective community. Community champions or "trusted sources" can advocate for and transmit the information to community members. Utilize guidelines for assessment of cultural appropriateness. An explanation of the materials' quality assurance process will build credibility with providers and the public.

Formats:

Participants listed several formats and formatting issues that may aid in producing materials and systems more likely to resonate with and be used by a target audience. Some immigrants, as with some American-born people, are not literate in their own first language(s). This does not reflect lack of knowledge or understanding. Many cultures have a strong oral tradition and may not have a writing system, or the written form may be a little-used recent development. Preferably a system or specific materials could be available in multiple formats, such as written and oral or audio, based on community needs and traditions. Visual formats such as pictorial and video materials are helpful for people with limited reading skills or visual learning styles. Another population requiring some adaptation of materials is those with hearing loss.

For readability in general, participants expressed, materials should not have too many words and not enough pictures.

MedlinePlus.gov's multimedia slideshow tutorials have tremendous potential for being adapted to different languages and cultures. Some are now available in Spanish and there are a few Vietnamese adaptations as well. As of June, 2007, there are over 165 tutorials available at <http://www.nlm.nih.gov/medlineplus/tutorial.html>.

One person mentioned the potential inherent in video interpreting technology, in which each participant can see the other on each end.

Logistics:

Participants made several suggestions for the structure of a system for managing and disseminating culturally and linguistically appropriate materials. The group discussed the

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possibility of a systematic arrangement with defined roles for participants in order to gather, review, and disseminate information. Materials could be developed at the local level by or with trusted sources (referring to community members who have the confidence of their peers as trusted sources of information), these resources then gathered at the state level for centralization, and fed into a national resource such as the Refugee Health Information Network. The system should have the ability to identify holes, identify overlap, and avoid redundancy. Participants identified the difficulty a provider has in assessing quality of materials in unfamiliar languages, and it was suggested that materials for inclusion be required to have a one-two-one English translation available so that the provider ostensibly can know the item's content, although even then, it's impossible for the provider to assess language quality. The system should have a review process to evaluate or verify quality at the time of submission and subsequently review it again at a later date to determine whether it should stay in the system or be removed. For example, RHIN has a policy in which each item must be reviewed every 2 years to determine if it's still appropriate for inclusion.

Participants also suggested a current awareness service of some kind, such as an RSS or Atom feed to alert users about of events and conditions such as additions, deletions and system status.

3. What are some organizations and programs that you think are most successful in connecting service providers and members of the public with culturally and linguistically appropriate health information, and why?

(Listings are interview/focus group participants' suggestions)

- [Ethnomed.org](http://ethnomed.org)
- Spiral (<http://spiral.tufts.edu/>)
- 24 Languages Project (<http://library.med.utah.edu/24languages/>)
- NN/LM Consumer Health Information in Many Languages Resources (<http://nnlm.gov/outreach/consumer/multi.html>)
- Grant project we [a participant] did at Children's [Seattle] with funding from NNLM for parents of children with special needs—in addition, a refugee organization in another state replicated it for their community.
- Parent to Parent of New York (<http://www.parenttoparentnys.org/>)
- Linking community groups with public libraries
- Hospital libraries are learning to serve needs of patients in addition to providers. Highline's Planetree library, Children's Hospital's health resource center, Swedish's health resource center
- Local public libraries. Some are working hard on this; others are problematic, for example at one local library a participant encountered staff that was reportedly unaware that the public can access PubMed.
- Cross Cultural Health Care Program's publications and work (<http://www.xculture.org>)
- International Community Health Services in Seattle and similar groups working in local communities. ICHS is now serving East African and other communities in addition to Asians and Pacific Islanders. (<http://www.ichs.com/>)

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- Asian and Pacific Islander Women and Family Safety Center, which is sensitive to men's and children's needs in as well as women's. They are getting better and better. (<http://www.apiwfsc.org/apiwfsc/index.html>)
 - Refugee Women's Alliance (ReWA) does very well though may be having growing pains as they serve a greater array of communities and hire people from an ever-increasing variety of backgrounds. (<http://www.rewa.org/>)
 - Culture Clues from UW medical center. They are provided both online on the intranet and the UW Health Sciences Library's Healthlinks site but also various clinics in the center have laminated print versions. People were given rings with which to organize them, and new additions are added to the rings as they become available. (<http://depts.washington.edu/pfes/cultureclues.html>)
 - Ohio-- One of the best I've [participant] seen is Ohio State. Totally seamless, all available. From patient to academic side. From what patients or providers want to look at, you almost didn't realize you were moving. Very intuitive, well done. I haven't seen much written from Ohio State.
 - WIC (Women, Infants and Children Nutrition Program) has a well funded network and they encounter more LEP people than any other department at DOH. They do a good job staffing offices with people who speak various languages and they provide multilingual materials. (Washington's WIC program: <http://www.doh.wa.gov/cfh/WIC/>, National WIC Association: <http://www.nwica.org/>)
 - Immunization programs such as CHILD Profile. CHILD Profile has produced materials in more languages than any other department at DOH. (<http://www.childprofile.org/>)
 - Most of DOH is far behind these previous two. In systems where they encounter a more people with limited English proficiency, such as hospitals, schools, and the legal system, they have to come up with ways to appropriately serve people. It's easier to see progress in those fields. DOH is trying to establish a system for all DOH departments to help them figure out how to consistently communicate well, be it step by step, protocols, or whatever can be done to make it easier for a program.
 - National Network of Libraries of Medicine (NN/LM). NN/LM does not fund top heavy projects. The funds must go to the community. Programs must be community-based; we have to be convinced that enough members of that local population group are involved for the information to be trustworthy and broadly applied. (<http://nnlm.gov/>)
 - **Culture & Clinical Care.** Edited by Juliene G. Lipson and Suzanne L. Dibble. San Francisco: UCSF Nursing Press, 2005 (A book).
 - National Center for Farmworker Health (<http://www.ncfh.org/>)
 - There's a group in California that took what we had done with multicultural diabetes at Harborview and really expanded on it.
 - The National Cancer Institute (<http://www.cancer.gov/>)
 - A project of the National Cancer Institute and Harborview Medical Center
4. **Quality control: Are there programs or techniques in existence that you think are particularly successful in ensuring the quality of materials and/or the programs that provide access to them?**

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Community input and review:

Participants stressed the importance of community input and review more often than anything else. The Cross Cultural Health Care Program's *Voices of the Communities* project and subsequent community profiles employed a process in which profiles were either written by a community member or a community member and CCHCP staff. Each profile was reviewed by other community members and any resulting changes were incorporated in the final product. The process resulted in excellent products. The UW Medical Center employs a similar process for its *Culture Clues*. The medical center has advisory councils in specific service areas such as oncology or maternal care, which include patient advisors from various cultures. The advisors' input is taken seriously and their opinions are often sought; this serves as a quality control measure. Another participant described the method used by their organization as a health education model. They get input from the intended audience before they write anything, learning their concerns and barriers to whatever is trying to be communicated, and tailor the product to their needs. Newly developed materials are tested with people from the target audience to make sure it's clear, understandable, and compelling. Not all of their materials are developed this way, but by policy they are supposed to be.

Participants again stressed the need to determine the audience's needs and wants from the audience, rather than paternalistically telling them what they "need."

Certification of translators and interpreters who produce and disseminate materials, amongst other roles, also helps with quality control.

Other techniques, issues, and projects mentioned:

- MedlinePlus—they have a Spanish language interface but if you don't speak Spanish you won't start there. I [participant] appreciate that there are unique materials to both the Spanish and English language versions. When there is an actual verbatim translation, when I can read in English exactly the content to be delivered in Spanish, that is noted on the site. They note "also available in Spanish" or "also available in English."
- We [UW Medical Center and Harborview] were trying to develop short videos demonstrating medical procedures in the emergency room for the purpose of teaching. We didn't want to do all of this if someone else had already done it. But even when someone else had already made a video on a subject, we could not convince Harborview to use these because it wasn't precisely the way they want to teach it at Harborview. We had to make original videos after all. It seems like a money waste, and I'm afraid that will happen with translations.
- NN/LM—we like to think NN/LM is very careful and has a quality control handle on what shows up on their website and in print. Other organizations may not have the limitations NN/LM has, such as being limited by the strictures of evidence-based medicine.
- Inventory systems can keep outdated materials in distribution in systems where they won't make a new one until the old one runs out.

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- HONcode--(Health on the Net Code of Ethics, <http://healthonnet.org/>) When health information first went online, I [participant] used to see the HONcode logo, an industry- and community-wide recognition of the need for quality control and ethical standards...it was like the Good Housekeeping Seal of Approval. There was a strong effort years ago to have that kind of code of ethics for health information sites and I don't know if that has persisted or not because it's a tough thing to enforce.
- Refugee Health Information Network (RHIN, <http://www.rhin.org/>) has a review process for submission and materials must be periodically reviewed to determine if they should be retained.

5. Briefly, what subject areas and languages do you think are the best covered and most available, and what are some subjects and languages for which it is most difficult to find quality materials?

- a. Subjects with abundant culturally and/or linguistically appropriate information available:
 - Immunization. Some states have materials in 15-20 languages.
 - Diabetes
 - Heart disease
 - Obesity
 - Nutrition
 - Physical activity
 - Common conditions
 - Materials on subjects with the most demand for volume are developed first
 - Women and infant health
 - Emergency preparedness and homeland security, because it is a big priority with the government right now. Ten years ago it was STDs.
 - Cancer
- b. Languages with abundant materials available:
 - Spanish. Parts of MedlinePlus and Micromedex are available in Spanish.
 - Russian
 - Vietnamese
 - Refugee and immigrant groups prominent locally (Seattle area) are covered by Ethnomed.
- c. Subjects in need of more culturally and linguistically appropriate materials:
 - Rare disorders
 - Autism/Aspergers spectrum
 - Birth defects
 - Genetic diseases
 - Forms
- d. Languages or cultural groups for which more materials are needed:
 - Russian. Asian languages (Chinese, Vietnamese) used to be the core languages at our hospital, now it is Russian for which there is much need but little material.
 - Vietnamese

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- Chinese (there are multiple dialects but most of them are mutually readable in written form).
- There are many new Chinese immigrants who are illiterate in their own languages.
- Toisanese/Hosianese/Taishan—a village dialect of the Yue or Cantonese language from Guangdong, China, spoken by many older immigrants who've been in the US for decades. The language can even be distinct within a community like Chinatown. There is no standard written system for this language; although Chinese characters are used, there is not a character for everything in Toisanese. [There is no standard Romanization system either, according to Wikipedia at http://en.wikipedia.org/wiki/Taishan_dialect.]
- American Indian and Alaska Native communities
- Hearing impaired populations
- Micronesian languages
- Somali
- African languages and dialects
- Eastern European languages
- South Asian languages that are not common in Seattle but may be encountered by providers in Washington because they are common just north in Canada
- New immigrant groups have to be assessed to determine their specific needs
- For many people, their first, second or third language are all languages we've [participant's organization] never heard of

6. What are some proprietary and copyright issues affecting widespread access to culturally and linguistically appropriate health materials? If your organization produces such materials, are they available to the general public and if not, why not?

We prefer to use information that is in the public domain/we produce materials for the public domain

The participants generally preferred to use and recommend materials that are in the public domain and not subject to copyright, and most of the organizations they represent want their information to reach the public unhindered. Materials produced by or funded by the Federal and most state and local government generally can't be copyrighted and are in the public domain. Increasingly, such materials are posted on the Internet. In addition, a participant stated that if an agency is producing something with outside support, they should be required to make it freely available. Materials intended only for health professionals were the major exception, as explained below.

Copyright issues:

A participant noted that she tries to remind people to respect copyright, as in their zeal to share information people sometimes ignore it. Hospitals may not want information available to competitors.

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Images can present a great challenge when developing materials, because digital protections can be fuzzy and permission to use images can take weeks. Programs that constantly develop material often don't have time to wait.

Medical concerns and liability:

Some institutions do not provide public access to all their materials because they deal with specific procedures and situations that require a health professional's assistance for correct use. For example, instructions for post-surgery wound care might be given to a patient for home use *after* a health professional guides them through the process. Institutions and providers fear liability and potential misinterpretation of materials. Materials may have a disclaimer saying this is not meant for self-diagnosis, please consult your doctor. According to one participant, "You end up having so many disclaimers on it it becomes almost tedious. I think that's probably the issue more than copyright."

Ambiguity about distribution and copyright:

Some participants weren't certain of distribution policies in place for their institution's original materials. Information is regularly handed out to patients and visitors without apparent concern about replication. One "grey area" is the status of individuals' presentation materials. Many times a physician or other professional presents a talk or at a brown bag lunch or other event, and the presenter may or may not hand out hard copies of the presentation notes. Even in cases where the presenter is willing to hand out the notes, audience members often don't know if they may reproduce it. On the other hand, a participant noted, much medical information overlaps and is common knowledge among health professionals and scientists and people just phrase it differently, so how can someone say "This sentence is mine"?

Other reasons to share or not share:

One participant said that her institution wants to make all of their patient education materials publicly available but they have not worked out how to do it yet—a technology barrier rather than a policy barrier.

- 7. What infrastructures exist in Washington State that could be better utilized and appropriately utilized to improve access to culturally and linguistically appropriate health materials, and how? (For example, the State Library, National Network of Libraries of Medicine/Pacific Northwest Region, WA Department of Health)**
 - a. What are some pros and cons of these infrastructures?**
 - b. How about national and international infrastructures? (For example, Refugee Health Information Network, National Library of Medicine)**

Libraries

Public libraries were noted as a place some members of underserved communities will go, as well as community resource centers. NN/LM has a tremendous role in funding health information projects in libraries and community organizations, reaching many public librarians who know the community groups and community information needs in their area. The Washington State Library, while it does provide support for public libraries, may or may not be

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able to play a role, as it has been cut back drastically in recent years. Sadly, King County Library System no longer has a health librarian. Seattle Public Library has had little involvement in providing culturally and linguistically appropriate health information, although they appear to prioritize providing books and other media in various languages other than English. Yet 20% of reference inquiries received by a sample of public libraries in the late 20th century concerned health.⁵ The public libraries are a remarkable infrastructure that can be utilized better than they are currently for culturally and linguistically appropriate health information.

Washington State Department of Health

Participants suggested that the DOH could have much to contribute to a system for culturally and linguistically appropriate health information. They expressed that the Department of Health works very hard at providing culturally and linguistically appropriate programming on specific projects, although departments are approaching it independently, are at different stages, and could benefit from more inter-departmental exchange.

In particular, H.E.R.E., the Health Education Resource Exchange (<http://www3.doh.wa.gov/here/>) was cited as a potential prototype for such a system. A participant suggested that collaboration between H.E.R.E and the State Library could potentially be quite powerful, although as noted earlier, the State Library has been scaled back. Considering that some participants reported not understanding some connections between H.E.R.E. and other programs, or thinking the project had lost funding when in fact it is currently funded and revamping its web site, it would appear that H.E.R.E. is not as well known or publicized as it could be.

As the State health department, DOH is in contact with all local public health departments in the state and in some respects, already serves as an infrastructure for submitting, collecting, and sharing health information, as in the case of H.E.R.E. and to a lesser extent the Tobacco Prevention and Control Program.

Refugee Health Information Network (RHIN) and MedlinePlus

The Refugee Health Information Network (RHIN) was named as a home for a national infrastructure on culturally and linguistically appropriate health information. Indeed, RHIN appears to envision that role for itself. Participants noted that RHIN needs a big influx of funding for promotion and development. They expressed trepidation because RHIN is currently a volunteer effort as opposed to established systems such as PubMed.gov and MedlinePlus.gov to which RHIN would like to be comparable. It has received support from the National Library of Medicine, and that relationship could provide RHIN the credibility, stability and publicity necessary to establish it firmly.

MedlinePlus itself has great potential for this type of role. It is a quality-controlled portal to full-text health information from numerous sources, with a growing Spanish version and user-friendly tutorials.

⁵ Gillaspy ML. "Factors affecting the provision of consumer health information in public libraries: The last five years." *Library Trends*, 53(3), Winter 2005, p 480-495.

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On the downside, some participants expressed mixed feelings about [national infrastructures]. They can be hard to maintain. National resources can't focus themselves on local needs, and there are sometimes substantial linguistic and cultural differences between seemingly similar communities across the country. Something in Spanish from New Jersey may not work for Spanish speakers in Washington State. The role of national organizations, they suggested, should be to fund local projects rather than produce information.

Unlike many national organizations, RHIN is trying to be international and is innovative and courageous enough to provide materials from other countries.

Special interest groups and associations:

Another type of organization that can play a national role is groups serving a particular health interest, like the National Hispanic Institute on Aging, and professional associations such as the Society for Public Health Education (SOPHE). A participant stated that libraries are not the first natural partner, and perhaps SOPHE is a better. Interpreters are more connected to SOPHE and providers than to librarians.

Local infrastructures:

Participants mentioned community colleges, CHOICE Regional Health Network (<http://www.crhn.org/>), local health institutions, and the Seattle Department of Information Technology's Community Technology Program (<http://www.seattle.gov/tech/>) as local infrastructure resources. The Seattle technology group, a participant described, gets people working together in a reasonable way. They have created a center for people with communication issues, they know the latest technology, and they focus on ESL and vocational needs. They have worked with East African communities, Ethnomed, and others.

Doubts were expressed again about translation quality; it was mentioned that UW Medical Center has many direct translations but you don't know if they are culturally appropriate and "they probably aren't."

Other organizations:

Other types of organizations and services that potentially or already are community links to culturally and linguistically appropriate health information include faith-based organizations, listservs (which tend to serve professionals), blogs, and newsletters. The Federal government's Agency for Healthcare and Quality (AHRQ, <http://www.ahrq.gov/>) has potential for a clearinghouse function, guidelines for producing appropriate information, and quality measures.

Existing large entities need to connect meaningfully with communities:

One concept repeatedly mentioned was the challenge for large organizations, whether local or national, to meaningfully work with communities and community-based organizations. The large entities named here must learn to connect locally with local organizations that meet the needs of these community groups in order to put information where they'd like it to be. An infrastructure for culturally and linguistically appropriate health information would need to reach into communities to grass roots groups, church groups, public libraries, and other places people go. According to some participants, large infrastructures are utilized mainly by people in

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the know; even many professionals in related fields aren't aware of them. These infrastructures are often designed not for the general public but for specific agencies such as Planned Parenthood or WIC, and agencies focus on their own interests. Meanwhile, grassroots organizations tend to know their community but are especially tight for funding. One participant suggested that the Go Local projects of the Regional Medical Libraries are a natural fit—funding from the national level, knowledge from the local level. A participant mentioned the NN/LM Pacific Northwest Region's Consumer Health Information Advisory Group, saying it does a wonderful job but is challenged to make a strong local connection with some of its projects.

Reasons grassroots organizations may not be reaching out to each other and to larger infrastructures:

There are also challenges on the local, grassroots end in connecting to larger infrastructures. For example, one needs to be vocal towards large agencies about one's community's needs but every community has different needs and styles and conventions. One participant explained that while in the dominant culture of the United States, "The squeaky wheel gets the grease," in Japan, for example, "The quacking duck gets shot." Such potential differences need to be considered when encouraging people to ask for what they want and present what they can bring to the table.

Another issue is that for various reasons some people and organizations don't want to share; they want to hoard information for themselves. This, a participant explained, is rooted in oppression issues. People feel that they need to hoard as much of this information as they can to get ahead. We need to change the mindset of people, explained the participant, but it's really hard because it's been ingrained for so long. There is a need to educate people both in large agencies and grassroots groups about oppression and about undoing institutional racism in order to reverse this and other barriers.

Additional commentary:

- Participants expressed concern for the needs of providers in rural areas who must rely on distant sources or their own information when discharging patients and in other situations.
- In an example of why standards are needed, Microsoft and localization companies, participants believed, do very poor translations.

8. What standards and conventions should be utilized or adhered to in organizing culturally and linguistically appropriate health information? In producing information?

Specific standards and techniques:

Originally, this question was envisioned to address electronic cataloging standards, but that's not where it went. Participants gave a variety of standards-related comments regarding production of information, quality control, and relevant professional fields.

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According to one, a big step was made with the CLAS (Culturally and Linguistically Appropriate Services) Standards.⁶ The CLAS Standards which address language are considered Federal mandates, but the speaker would like to see the rest of the CLAS standards be mandated as well.

Testing and certification of translators and interpreters was cited as very important, and so was testing materials with the intended audience.

The health educator field and its association SOPHE may have some standards for patient education materials. HONCode was mentioned again, and its status as a non-governmental organization was cited as a good thing. If not the HONCode system, then some kind of review process for medical accuracy should be in place.

Participants noted that different fields and professionals are moving in different directions with standards, and collaboration and agreement are easier said than done. At least one participant pointed out that while standardization is good for submitting things to a large system, there can be trade-offs in flexibility. Some of the best materials are developed on-the-spot to meet a need. Often if materials are submitted to a system, the submitter does not have a sense of ownership or responsibility about following it up and submitting updates. There needs to be a mechanism to avoid retaining outdated information.

Creating culturally competent materials:

Many comments regarding standardization involved issues of cultural competency. Materials should be developed in languages as needed and desired by that population, rather than simply translating English-language items into other languages. Producers must think beyond straight translation to developing materials for specific needs. Also as noted earlier, participants said that if one identifies a cultural group they want to work with the people must be represented at every step of the process. Language register and social class are also considerations.

In addition, outside producers of information and systems need to be aware of communities' past experiences with researchers, health care, and the public health establishment. Although a community's culturally specific needs may be new to outsiders in health and social services and academia, being asked for information by academics and government agencies may already be redundant and people may be disillusioned. Communities, a participant explained, can become frustrated, thinking "why do we keep going through these processes, why are you asking us again," when they didn't see results in the past.

Usability:

Several comments concerned usability. A system needs to be simple for providers and patients to find, otherwise they won't use it. It should be "sort of in their face" or it won't get used. It should be customizable from the user's perspective. The interface and the materials it accesses should have a 6th grade reading level. Materials in languages other than English should have an English translation, for reference.

⁶ For additional information on the CLAS Standards, see the U.S. Department of Health & Human Services Office of Minority Health web site at <http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15>.

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MedlinePlus's interactive tutorials were mentioned again.

- 9. What sectors or populations do you see as major stakeholders whose participation is necessary to provide and make high quality, culturally competent information accessible for service providers and the public? (examples: community leaders, community health workers, public libraries, clinic staff, educators)**

Providers and health workers:

- Community health workers
- Clinic staff
- Health educators
- Nursing staff
- Physicians
- Hospitals

Communities:

- Community leaders
- Regular people from the communities
- Community group representation itself would be an expansion of the examples given.
- Everyone has a stake. Some people who might be seen as community leaders don't see themselves that way. The perspectives of regular people are as important as CEOs and others in prestigious positions. Amongst all the people who come up with great ideas, many are regular people whose ideas are just as good as those of highly paid CEOs. Maybe if we would listen to the common person we wouldn't have the problems that we do now. We keep doing the same things over and over when it's already been proven that a lot of these things just don't work. So let's start listening to somebody else, give someone else a chance because they probably know better.
- People from communities should review every item.

Local government infrastructure and related agencies:

- Local health departments
- Emergency preparedness people
- 211
- Firefighters
- Public libraries
- Educational institutions
- ESL programs. Use health as topic to learn English.

Related businesses:

- Landlords
- Major employers
- Health insurers

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- Graphic artists

International:

- World Health Organization
- Other countries: Singapore, for example—people in Singapore had faith in their government’s actions regarding SARS. They provided really good outpatient information. There should be a good link to different cultures in other countries.
- We usually don’t even consider international sources as viable. In other countries people think if it came from US it must be good; meanwhile Americans think the same thing and it doesn’t occur to people in the US to try international resources. They may do different things in different countries that work just as well as US medical techniques.
- Other countries using other languages have lots of good info but that’s hard to get to if you don’t speak the language.

Other:

- I see three major groups: 1. Community and its leaders. 2. Practitioners distributing it to communities. 3. Librarians—less prominent but have much to offer [because of how this person expressed this, it is remaining intact rather than being distributed into other categories]
- Including graphics that are customized for communities

10. Who or what do you think should or could dedicate funding to developing, improving and sustaining these services?

Federal agencies:

- There’s commitment within local, state, fed government on this. I [participant] particularly like the focus on federal government sites to be more readable and provide lower literacy materials. Government agencies have a stake in that.
- Federal government
- National Library of Medicine and Regional Medical Libraries (NLM and RMLs, <http://www.nlm.nih.gov/>)
- National Institutes of Health (NIH, <http://www.nih.gov/>)
- Centers for Disease Control and Prevention (CDC, <http://www.cdc.gov/>)

State and local agencies:

- State libraries
- National Network of Libraries of Medicine regional medical libraries
- Hospitals

Local organizations have the knowledge, large infrastructures have the means:

- Local organizations know the community; federal organizations have the money

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- Everyone collaborating lower down at state levels and then putting their materials and programs in a database maintained by one of these agencies, but they aren't carrying the full cost.

Special interest groups/related associations:

- Related groups like American Lung Association

Commercial entities:

- Pharmaceutical companies
- Think unconventionally. I [participant] went to the egg companies to seek funding for immunization work because one egg is required for each dose of flu vaccine.
- Specialty food companies

Large foundations:

- Large foundations such as the Bill and Melinda Gates Foundation should be contributing to health needs in their own backyard and not just in developing countries.
- Kellogg Foundation, Robert Wood Johnson Foundation

Other:

- Taxpayers

11. Is there anything else you would like to add or discuss?

- I [participant] am tired of people denigrating earlier efforts based on what we know now—they were doing the best they could with what they have. I'm thrilled with the progress we've made since.
- People ignore those things and things will continue to be the same, and institutional racism continues to exist. We'll all continue to have our jobs, but it would be nice to be able to sit back and know your job is done.
- I [participant] think in public health there's a strong desire to do something but there is no guidance or resources. I think if there were clearer ways for people to apply what they know, have contact ...if it was just easier to communicate their stuff in other languages there'd be a real willingness in public health.
- Some existing barriers to wider access to appropriate health care information? Knowing where to look. I think if there were a single portal, well-known and well-trusted, it would be so much easier.
- As long as you can get stakeholders to realize they are stakeholders. There's a lot of passing the buck.
- The Federal Government is not a model that's going to work, look at the current administration, it cares nothing about health.
- Administer process control. The Board of Health should look at it from a process point of view. Get a process control expert who can come up with something better. This is different from strategic planning. The goal of it is to tighten all the inefficiency in a system.

Themes

Several themes emerged again and again throughout the focus group and interviews, as well as literature read for this project.

Involve the community! Cultural competence is impossible without it.

This theme was repeated over and over by interview/focus group participants, as well as carrying over from nearly every Cross Cultural Health Care Program project involving community health. At CCHCP an ethnic community profile is not considered complete or valid until it has been reviewed by whoever is being profiled. In CCHCP's Office of Minority Health CLAS Standards best practices research project, *relationships* stood out as the key ingredient for providing culturally and linguistically appropriate care. This echoed in every best practices site visit performed for that assessment. Every institution that successfully served its underserved communities built relationships with the community, hired from the community, determined needs based on community input, and integrated services vital to the respective community members' well-being.⁷

This is no less the case with providing culturally and linguistically appropriate health information. As Alison Pence⁸ (community-based health education and cultural competence/anti-racism training) said in her interview "The perspectives of regular people are as important as CEOs and others in prestigious positions. Amongst all the people who come up with great ideas, many are regular people whose ideas are just as good as those of highly paid CEOs. Maybe if we would listen to the common person we wouldn't have the problems that we do now. We keep doing the same things over and over when it's already been proven that a lot of these things just don't work. So let's start listening to somebody else, give someone else a chance because they probably know better."

Community buy-in is a must. Communities and their grassroots organizations sometimes distrust large institutions such as hospitals, universities, and large foundations. To large funders, large institutions look better equipped and more prestigious and more educated than grassroots organizations. Whether or not they are, they may not have the necessary understanding and personal investment to succeed in work with communities. They can look like the "Mansion on the Hill," or the "Monster on the Hill" as one East Baltimore resident and human service provider once described neighboring John Hopkins University and its hospital. Much research is conducted regarding underserved communities, but often the communities who put out effort to help see no benefit in return. Every year, fresh-faced well-meaning university students want to go into communities and do studies as if community hasn't accommodated the same thing over and over before. People get jaded.

⁷Putsch R, SenGupta I, Sampson A, Tervalon M. *Reflections on the CLAS standards: Best practices, innovations and horizons*. Seattle: Cross Cultural Health Care Program, 2003.

<http://www.xculture.org/research/downloads/CLAS.pdf>

⁸ Alison Pence indicated she didn't mind being credited by name in this report.

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Participants mentioned that collaboration is more easily said than done, with all the difficult projects occupying organizations' time, and organizations' necessary focus on their own concerns. Groups like the Community Campus Partnerships for Health network find ways to break down these barriers and bring in the best of both worlds.

Local groups know their communities; the big guys have the resources

Closely related to the prior theme, participants described this dichotomy repeatedly. Local people and local organizations serving communities are the subject experts. Similarly, in the context of the WA DOH Tobacco Control and Prevention Program and its Tobacco Disparities Advisory Committee (TDAC),⁹ community-based advisors and contractors implored the State program to include more of their home-grown programming and health promotion materials for wider distribution because they felt these were more successful and relevant to Washington's communities than State-prepared programming. A program that is strictly national or even only state-based cannot know the needs and subtleties of local communities.

This is why a multi-level system makes sense. Materials produced by local projects and collaborations, grassroots efforts, community health clinics and other community-based health and services programs, and mutual assistance associations could be centralized at the state level and fed into a well-funded and well-organized national network or agency such as the Refugee Health Information Network (RHIN) or MedlinePlus or even the Agency for Health and Research Quality (AHRQ). While the infrastructure should be at state and national levels where funding might be more reliable and technology more stable and maintainable, much original material should come from the local level. Agencies such as the National Network of Libraries of Medicine and sometimes the Office of Minority Health prioritize funding small-scale local projects. The infrastructure at the state level of this system wouldn't necessarily have to be hosted by the state government; another relatively stable large entity such as the University of Washington (home of the Regional Medical Library for the Pacific Northwest) could host it.

In Washington's case, a potential prototype already exists in the form of the Washington State Department of Health's H.E.R.E. in Washington (Health Education Resource Exchange, <http://www3.doh.wa.gov/here/>). H.E.R.E. brings together community-based programs and other health promotion programs, materials, bibliographies, and professional resources for health promotion professionals in Washington. According to director Don Martin, who has put a tremendous amount of work into the project, H.E.R.E. is currently well-funded and undergoing a makeover.

Make it publicly visible and easy to use

⁹ Cross Cultural Health Care Program has contracted with the WA DOH's Tobacco Prevention and Control Program for several years to help the program in its efforts to collaborate with communities affected by disparities in tobacco-related health issues, moderate TDAC meetings, provide support and advice, and perform CLAS-based cultural competence assessments.

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Despite the proliferation of new materials, much culturally and linguistically appropriate health information is buried where only dedicated searchers with time to spare for it can find it. A great web site may stick in one's mind and be turned over and over to the neglect of other equally good resources. Much effort goes into gathering links together on a site to the point where there's an overabundance of links collections referencing many of the same materials, linking back to each other, and leading to more links and links. If there were one or a few standard places that had great coverage of rich information and good quality control, with a stellar reputation and reliable infrastructure and support, this could simplify the situation and save time and money for users. Even MedlinePlus needs to promote itself better, as commercial competitors like WebMD seem to be more well-known.

Many quality sites are geared to professionals of some kind, rather than regular people. Participants insisted that they want something simple and obvious to use, as automatic as other functions we take for granted today like playing a DVD. They'd like to be able to push a button and out comes the right stuff. They want to see it in places people go, like on service providers' computer desktops, in clinics and churches and community centers, in salons and barbershops and other neighborhood businesses. The Seattle Technology Program, which has worked with immigrant and underserved communities to increase community technology access, has been able to create technology centers in hundreds of public and private community locations in King County.¹⁰ A good health promotion/education database tool could be integrated into this type of service. Similarly, the health sciences library at the University of Rochester Medical Center set up internet connected computers in six inner-city African American churches and one community center, and conducted workshops training church and community members to use quality health information such as MedlinePlus. A more expanded outreach program with underserved communities intends to follow this successful, modest first effort.¹¹

There may be much to learn from today's most popular web sites and search interfaces such as Google, with their easy-to-use, uncluttered, but highly effective search technology, and maximum public exposure. Similarly, library and literature databases have long made available different levels of search formats, with a basic search for most of us and an advanced search for those interested in learning it.

Current awareness functions such as RSS or other alerts services could keep health educators and other users abreast of new additions in their interest areas. Providers should have a mechanism to be aware of what kinds of information patients are seeking.

Another facet of usability and visibility is training for both providers and the public; the NN/LM and groups like Seattle's Community Technology Program are current and potential providers.

Implement standards for translation quality and for determining inclusion

¹⁰ Seattle Department of Information Technology, Community Technology Program. *Community technology directory*. Seattle: CTP, 2007. <http://seattle.gov/tech/techmap/>

¹¹ Sollenberger J, DeGolyer C, Rossen M. "Internet access and training for African –American Churches: Reducing disparities in health information access." In *Outreach services in academic and special libraries*. Kelsey P, Kelsey S, eds. Binghamton, NY: Haworth Information Press, 2003.

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Many participants expressed frustration over the difficulty in determining quality of materials, especially materials in unfamiliar languages. A state or national online system for culturally and linguistically appropriate information would need quality control functions at the point of submission. A system of medicine, language and culture experts could review materials for medical accuracy, cultural competence, translation quality, and usability. Trained and qualified interpreters, translators, and cultural navigators or advisors could help with this, as well as public health workers, librarians, health educators, and medical professionals. This should happen at the state level or lower, although a national system might need to use additional clarification on target audience and language and geographic source.

Redundancy and overlap and detecting gaps are another quality control issue. Whether automatically or manually, the system should be able to tell the submitter what else is already in the system on the topic in question and help them determine whether what they have is distinctive enough to include. There should be a monitoring system of some kind that would keep track of subject coverage and keep the system up to date with emerging health issues. A periodic review process should be in place to determine whether to retain, replace or delete older items.

While this report focused on health information materials, participants frequently referenced the importance of community health workers and training. The efficacy of transmitting information person-to-person is still going to be higher than that of materials. Nevertheless, the creation and dissemination of culturally appropriate health materials is a vitally worthy component of improving the State's health and reducing health disparities.

Resources for Culturally and Linguistically Appropriate Health Information

Creating a list of all major sources of culturally and linguistically appropriate health materials would by necessity be an ongoing project beyond the scope of this report. The following is just a few of the best and richest, some of which hold potential for organizing and disseminating culturally and linguistically appropriate materials state or nation-wide. Many of these resources were cited in the focus group and interviews, and many of the listings below contain commentary in addition to a brief description. The list is intended to be read as part of the report.

Producers, providers, and organizers of culturally and linguistically appropriate health information and services in Washington, and related organizations

Asian and Pacific Islander Hepatitis B Poster and Brochure Project

<http://www.metrokc.gov/health/prevcont/apiposters.htm>

Public Health—Seattle and King County produces posters and brochures on Hepatitis B in Cambodian, Samoan, Vietnamese, Pilipino (Tagalog), Korean, Laotian and Chinese. Materials may be ordered by email or telephone.

Asian Counseling and Referral Services (Seattle)

<http://www.acrs.org/>

ACRS provides extensive human services for Asian and Pacific Islander communities in the Seattle area. Services include mental health, substance abuse programs, support groups, a food bank, legal clinic, naturalization help, youth and family services, domestic violence services, senior services, and more. ACRS serves many survivors of war and trauma. The staff provides services in clients' native languages.

Asian Pacific Islander Coalition Against Tobacco

http://apicat.org/apicat/facts_resources.html

APICAT provides community outreach in Asian and Pacific Islander communities around tobacco prevention and cessation. This organization possesses vital coalition-building skills and experience.

Center for MultiCultural Health

<http://www.multi-culturalhealth.org/index.htm>

Health outreach efforts for African American and other diverse communities. Programs address tobacco use, prostate cancer, breast and cervical health, infant mortality, diabetes, heart health and more.

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Children’s Hospital and Regional Medical Center

Children’s Hospital produces high quality health information materials for parents in factsheet style, usually one to four pages each. Reading level is medium; though not low-literacy suitable, neither are they overly technical. Deceptively simple in appearance, these sheets pack plenty of information without being too dense with print.

Multilingual Languages Material

<http://www.cshcn.org/resources/otherlanguage.cfm>

Patient education materials in Spanish, Russian, and Vietnamese mostly regarding home asthma management, special needs, diabetes, and seizures.

Information by Diagnosis

<http://www.cshcn.org/resources/healtheducation.cfm>

Diagnosis information for parents on at least 22 conditions.

Culture Clues

<http://depts.washington.edu/pfes/cultureclues.html>

Produced by Patient and Family Education Services, University of Washington Medical Center, *Culture Clues* describes concepts and preferences relevant to providing quality care to African American, Albanian, American Indian/Alaska Native, Chinese, Deaf, Hard-of-hearing, Korean, Latino, Russian, Somali, and Vietnamese communities. An *End-of-Life Care* series is being produced, with info relevant to Latino, Russian, and Vietnamese consumers. *Culture Clues* is available on the web, and departments of the UWMC receive laminated copies in a package that allows additions as Patient and Family Education Services completes new profiles.

Ethnomed

<http://Ethnomed.org>

Ethnomed is one of the first and still one of the best web sites for cross cultural health care around. It’s a production of the University of Washington Health Sciences programs, Harborview Medical Center, and K.K. Sherwood Library at Harborview. Continuously evolving and expanding, Ethnomed combines information for health professionals and communities. Most of its content derives from local projects and collaborations addressing the health concerns of Seattle’s immigrant communities, including tools and reports. Ellen Howard, head of K.K. Sherwood Library, founded and directs Ethnomed.

Gay, Lesbian, Bisexual and Transgender Health (Public Health—Seattle and King County)

<http://www.metrokc.gov/health/glbtc/>

Directory of original and off-site health information specifically for and about GLBT people and families.

Hate Free Zone

<http://www.hatefreezone.org/>

Seattle-based organization advocating for civil rights. Hate Free Zone is not specifically health focused, but provides applicable information about immigration, access to services, worker discrimination, civil liberties and more.

The Health Status of American Indians and Alaska Natives Living in King County

Public Health—Seattle & King County in partnership with **The Seattle Indian Health Board**

<http://www.metrokc.gov/health/reports/aianreport.pdf>

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Seattle: Public Health – Seattle & King County, 2001.

This document provides health statistics on a number of subjects and also describes the American Indian and Alaska Native communities of King County.

International Community Health Services

<http://www.ichs.com>

Originally serving primarily Asian and Pacific Islander communities, ICHS provides a diverse clientele with full medical and dental services. Parts of ICHS's web site are available in Vietnamese and other Asian languages, though as of mid-2007 this aspect of the site was far from complete.

NPower Seattle

<http://www.npowerseattle.org/>

NPower Seattle helps Puget Sound Area non-profit organizations use technology to better serve their communities. Its suite of technology services for local non-profit organizations includes consulting and training. Services include office computer network installation and support, designing web pages, and database services. NPower Seattle is a member of the NPower Network (<http://www.npower.org/>), a national network delivering technology solutions for community organizations.

Project STEP (Spokane Regional Health District)

http://www3.doh.wa.gov/here/Projects/Project_Detail.aspx?ID=32

Tobacco reduction and prevention program for youth, developing culturally appropriate programming.

Public Health - Seattle and King County Digital Library

<http://www.metrokc.gov/health/library/>

A portal to full text and links on dozens of public health topics, this digital library includes a "cultural literacy" section and some materials in languages other than English.

Reach 2010 Coalition

<http://www.metrokc.gov/health/reach/diabetes.htm>

Reach 2010 Coalition seeks to reduce diabetes disparities in King County. Pdf files of culturally specific diabetes meal planners in Cambodian, Filipino (Tagalog), Chinese, Korean, Japanese, Samoan, Somali, Spanish, Vietnamese, and English. Also 100-plus page "Asian" cookbook in Chinese, Khmer (Cambodian), Tagalog, Korean, and Vietnamese. While the meal planners are adapted to the food traditions of the respective language groups, the recipe book is a mix of recipes from various Asian cultures, reproduced in five languages.

ReWA - Refugee Women's Alliance

<http://www.rewa.org/default.asp>

Culturally and linguistically appropriate services and advocacy for refugee and immigrant women and families, including programs addressing developmental disabilities, domestic violence, early childhood education, youth, parent education, family support, education and vocational training, and senior services. ReWA has worked in many ethnic communities and employs an especially diverse staff.

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Sea Mar Community Health Centers

http://www.seamar.org/es_index.htm

Sea Mar's web site is available in English and Spanish from this non-profit serving a primarily (but not exclusively) Latino clientele.

Seattle Department of Information Technology

Community Technology Program

<http://www.seattle.gov/tech/>

The Community Technology Program brings technology to Seattle neighborhoods. It supports and sponsors hundreds of Community Technology Centers (CTCs) in Seattle and King County, located in community centers, libraries, Boys and Girls Clubs, mutual assistance associations, children's homes, family resource centers, health clinics and human service agencies, churches, schools and other settings. They may serve families, youth, immigrants, single mothers, job seekers, or seniors. In collaboration with the communities they serve, CTCs provide technology training, access to information, increase civic engagement and improve digital opportunities to local communities.

The Community Technology Program's Free Wi-fi Pilot Program provides free wireless internet access in Columbia City, the University District and four downtown parks. Free wi-fi is also available at the Seattle Center House and Seattle Public Libraries. The Technology Program also offers free web hosting for community organizations.

The Community Technology Program's Technology Matching Fund (TMF) grant program "was established in 1997 to support the community's efforts to close the digital divide and encourage a technology-healthy city."¹²

A focus group participant pointed out that the CTP prioritizes health and language issues. Its reach and abilities are remarkable and the program seems an appropriate and promising link in networking access to culturally and linguistically appropriate information.

Spokane Regional Health District Data and Publications

<http://www.srhd.org/information/pubs/default.asp>

Spokane Regional Health District produces numerous health promotion materials for people and providers, including a head lice brochure in five languages.

StateHealthFacts

<http://www.statehealthfacts.org/>

Henry J. Kaiser Family Foundation

Click Washington on the US map for Washington-specific health facts. The limited "minority health" section is worth a look.

Tacoma-Pierce County Health Department Ethnic Senior Health Promotion Program

<http://www.tpchd.org/page.php?id=302>

Coordinates and provides culturally competent health promotion and disease prevention services at ethnic nutrition meal sites. The meal sites include: Hispanic, Cambodian,

¹² Seattle Department of Information. Technology Community Technology Program. "Welcome to Seattle's Community Technology Program." Seattle: CTP, 2007. <http://seattle.gov/tech/>

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Vietnamese, Filipino, Samoan, Korean, and Japanese. Additionally, Russian seniors meet at their apartment complex for health screening and promotion.

Pacific Asian Empowerment Program (PAEP, <http://www.paep-seattle.org/>) conducts similar services in King County for the Filipino, Lao, Mien, Hmong, Polynesian, and other Asian and Pacific Islander communities. The **Cross Cultural Health Care Program** previously had a similar program, the Health and Nutrition Demonstration Project, funded by tobacco settlement money granted by the state Attorney General, which in addition to cooking demonstrations and health screenings, led culturally appropriate fitness workout sessions API seniors could get excited about. Public Health – Seattle and King County’s **Come Taste Cooking Demonstrations** is a similar program with numerous community partners.

Tribal Connections

<http://www.tribalconnections.org/about/staff.html>

American Indian/Alaska Native community health and information resource portal supported by the National Network of Libraries of Medicine and the Bill and Melinda Gates Foundation. The site includes culturally appropriate health information, funding opportunities, education and training resources, and original articles.

Verbena Health

<http://www.verbenahealth.org/index.html>

Verbena “builds vibrant communities for lesbians, bisexual and queer women, and transgendered individuals through health advocacy, education, support services, and access to care.” Verbena provides a variety of culturally appropriate, innovative services and collaborations.

Voices of the Communities

<http://www.xculture.org/resource/library/index.cfm>

Cross Cultural Health Care Program, Seattle, 1996.

Profiles of Arab, Cambodian, Eritrean, Ethiopian, Lao, Mien, Oromo, Samoan, Somali, South Asian, Soviet Jewish, and Ukrainian communities in the Seattle area. Dated but still high quality. Newer, expanded profiles are available for purchase.

Washington Health Foundation

<http://www.whf.org/>

Elimination of health disparities is one of Washington Health Foundation’s priorities, along with rural health, healthy lifestyles, and improving public health. Its “Healthiest State in the Nation” campaign and other activities may provide opportunities for funding and collaboration for culturally and linguistically appropriate care and information.

Within Reach

<http://www.hmhbwa.org/forprof/materials/home.htm>

Formerly Healthy Mothers Healthy Babies of Washington, Within Reach produces publications and brochures for new mothers concerning immunization, breastfeeding, infant oral health, post-partum depression and more. Some items are variously available in English, Spanish, Cambodian, Vietnamese and Russian, including publications specifically developed for parents of particular linguistic and cultural backgrounds. Within Reach also distributes WIC outreach

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brochures in eleven languages. Some items are available in hard copy, some electronically, and some both. Within Reach also offers services in Spanish.

Yakama Health Fair

This health fair is organized yearly by Yakama Nation members and Yakama Indian Health Center. Dozens of agencies and hundreds of visitors attend this event which promotes healthy lifestyles and publicizes local health services and resources.

[Washington State Department of Health and Department of Social and Health Services programs](#)

CHILD Profile

<http://www.childprofile.org/index.html>

CHILC Profile, administered by the Washington State Department of Health and contracting with Public Health—Seattle and King County, is Washington’s Health Promotion and Immunization Registry system, which tracks all children born in Washington through age six in an effort to maintain high immunization rates.

Duwamish River Community Outreach Project

A WA Department of Health health educator and members of various immigrant communities collaborated to produce linguistically appropriate materials and presentations to alert residents to the dangers of eating fish from the polluted Duwamish River and Elliot Bay.

Environmental health site <http://www.doh.wa.gov/ehp/default.htm>

Print materials available for download from H.E.R.E. (<http://www3.doh.wa.gov/here>)

Public Health’s Shellfish Education Project provides a similar service regarding shellfish harvesting. Similar shellfish programs have been conducted in Thurston and Clallam counties.

H.E.R.E. in Washington (Health Education Resource Exchange)

<http://www3.doh.wa.gov/here/>

Under the direction of Don Martin at the Washington State Department of Health, H.E.R.E. is a clearinghouse of public health education and health promotion projects, materials and resources in the State of Washington. Its several sections include a searchable database of community projects, resources for educational materials, listing of health promotion professionals and their networking resources, health educator’s toolbox, events calendar, annotated bibliographies, other web sites, and H.E.R.E. newsletters. The educational materials section has incorporated the collection of materials originally compiled and reviewed by Elizabeth Comstock at Public Health – Seattle & King County and her review committee.

National Diabetes Education Program - Hispanic Community Outreach

<http://www.doh.wa.gov/ndep/default.htm>

The State Department of Health and Skagit, Whatcom, Yakima, Franklin Counties are trying to increase understanding and awareness of diabetes in Hispanic communities through interviews with health providers and public service announcements broadcast in Spanish, in-home health education parties in Spanish, Spanish-language informational displays at events, education of health care professionals at clinics, and other activities. Other priority populations include

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African Americans, Asian Americans, Pacific Islanders, American Indians, Alaska Natives and older adults.

Similarly, **Moses Lake Community Health Center's** health educator teaches diabetes education classes to diabetes patients in English and Spanish; a Russian offering is in the works.

Terry Carpenter, Moses Lake Community Health Center, 605 Coolidge DR Moses Lake, WA 98837 Phone: 509-765-5916

Journey Through the Healing Circle

<http://www1.dshs.wa.gov/ca/Fosterparents/journey.asp>

File last updated July 2005

This series about Fetal Alcohol Syndrome for kids and parents is a collaboration between Washington State agencies, traditional Northwest tribal storytellers, and health-care experts. Lots of entertaining animals, including a young iceberg-riding puffin who breaks out of an aquarium with some penguins, amongst other adventures. The series features portrayals of characters with FAS as able, intelligent personages whose unusual traits aren't necessarily bad, who find their way in the world despite challenging hurdles.

Tobacco Prevention and Control Program, Washington State Department of Health

<http://www.doh.wa.gov/tobacco/>

The Tobacco Prevention and Control Program works with several community-based organizations to reduce tobacco use in underserved communities. Some resources and descriptions of the program's work appear at the above address, but ordering or downloading the program's growing selection of linguistically and culturally specific materials requires visiting the Washington State Department of Printing site at <http://www.prt.wa.gov/>. The apparent absence of a link to this source on the Tobacco Program's web site is puzzling.

Washington WIC Nutrition Program

<http://www.doh.wa.gov/cfh/WIC/default.htm>

Produces WIC outreach flyers in 11 languages. Some additional WIC materials are also available in multiple languages.

Health resource centers in Washington

(not comprehensive)

Children's Hospital and Regional Medical Center

<http://www.seattlechildrens.org/>

Family Resource Center

http://www.seattlechildrens.org/our_services/support_services/family_resource_center.asp

Swedish's Family Resource Center provides health related materials, aids staff and patients with hospital-related questions, and serves as a place of respite away from the bedside. Features refreshments and computer workstations.

Its web site links to additional services including Swedish's Library & Information Commons, which serves the information needs of health professionals, patients, and families; the

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Children's Resource Line which provides guidance on a variety of topics involving parenting and child development; support groups; social work; and pastoral care.

Cross Cultural Health Care Program library and Northwest Resource Center on CLAS and Health Disparities

www.xculture.org

CCHCP makes available a great variety of information regarding immigrant and ethnic minority communities and the health issues affecting them, including linguistic access, informed consent, culturally competent care, medical interpreting and interpreter training, and much more. Its collection contains bilingual medical dictionaries in over 50 languages for interpreters' study. CCHCP also produces its own bilingual medical glossaries, community profiles, and reports which are available for purchase. CCHCP has pioneered renowned medical interpreter and cultural competence training programs, and conducts CLAS-based assessments of health and social services institutions. CCHCP's library/resource center is open to the public on weekdays; reference service is available. In 2006, CCHCP began seeking ways to fund an expansion of its library/resource center into the Northwest Resource Center on CLAS and Health Disparities, with support from the Office of Minority Health Region X.

Highline Medical Center's Planetree Library

<http://www.hchnet.org/services/planetreelibrary.php>

Highline's library caters to health professionals, patients, and families, with information at all levels of complexity. Planetree itself is not unique to Highline; it refers to a non-profit membership organization that promotes a health care model stressing patient-centered care in a healing environment. This forward-thinking, proactive model is amenable to valuing and developing culturally and linguistically appropriate care. Highline Medical Center is a Planetree member. For more information on Planetree, see www.planetree.org. Highline's librarian and members of the hospital's administration have expressed a keen interest in improving access to care for the diverse communities.

Kittitas Valley Community Hospital Community Health Library

<http://www.kvch.com/library.html>

The KVCH Community Health Library provides health and medical information to patients, families, students, healthcare professionals and others in Kittitas County. This health library began with community planning that involved local health care agencies, schools, libraries, businesses and the hospital, and it continues to operate with help from community fundraising. It promotes itself as "user friendly and free".

Swedish Medical Center/First Hill Campus

<http://www.swedish.org/>

Swedish's First Hill Campus has an accessibly-sited health resource center for patients.

Service directories and hotlines

211

<http://www.win211.org/>

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The Federal Communications Commission (FCC) has authorized telephone companies to use the designated phone number 2-1-1 for local communities to provide easier access to comprehensive information and referral service for health and human service resources. Washington State has eight 211 regions, and a particular agency has been designated to provide the 211 service in each area. The United Way spearheaded and leads the 211 program.

Washington's 211 Call Centers include:

Call Center	Location	2-1-1	Toll free number	Local number
Region 1, North Sound	Everett	2-1-1	1-800-223-8145	425-258-4227
Region 2, Peninsulas	Bremerton	2-1-1	1-800-627-0335	360-415-5892
Region 3, Western Counties	Olympia	2-1-1	1-877-246-1915	360-586-2800
Region 4, Southwest Counties	Portland, OR	2-1-1	1-877-501-0252	360-694-8899
Region 5, Pierce County	Tacoma	2-1-1	1-800-572-4357	253-572-4357
Region 6, King County	Seattle	2-1-1	1-800-621-4636	206-461-3200
Region 7, Greater Columbia	Yakima	2-1-1	1-877-211-5445	1-509-248-6726
Region 8, Eastern Washington	Spokane	2-1-1	1-866-904-9060	n/a

4People.org

<http://www.4people.org/>

4People.org is an online information and referral site for Washington State, based in Kennewick, searchable by county. 4People.org is a nonprofit and mostly volunteer-run, and lists a variety of human service agencies. Similar to the Crisis Clinic's "Where to Turn" directory but with statewide coverage, although not as complete.

Crisis Clinic

<http://www.crisisclinic.org/main.html>

Seattle's Crisis Clinic has operated an extensive directory of social services in King County for many years, in print and online. 2007 marks the 20th printed edition of its *Where to Turn* directory, and as King County's most comprehensive information and referral network, the Crisis Clinic has now been designated as King County's 211 provider. Although its database is large, the Crisis Clinic still misses many of the newer, smaller and sometimes ephemeral ethnic community associations.

H.E.R.E. in Washington (Health Education Resource Exchange)

<http://www3.doh.wa.gov/here/default.html>

See *Programs of Washington State Department of Health and Department of Social and Health Services* for details.

Regional, National, and International Resources

24 Languages Project

<http://library.med.utah.edu/24languages/>

A project of the University of Utah's Spencer S. Eccles Health Sciences Library and the Utah Department of Health, 24 Languages Project has digitized patient education materials in 24

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languages. The Eccles Library partners with numerous organizations to make information on various health issues available on the Internet for free. Formats include print, video, and audio. The site also links to selected similar sites. 24 Languages' strongest subject areas include communicable diseases and immunizations, and health-promoting lifestyles. The site itself is in English.

Healthy Roads Media

<http://www.healthyroadsmedia.org/>

A partnership of over a dozen community, government, philanthropic and academic organizations, Healthy Roads Media provides multimedia health information in fourteen languages. Materials originate from reliable sources that produce them through a quality controlled process, and information is reviewed regularly. Healthy Roads Media has grown and developed remarkably in its short lifespan and focuses on up-to-the-minute formats such as I-Pod movies. Users can access information by topic, format or language. Each language represented has an access page in that language.

National Network of Libraries of Medicine

Consumer Health Information in Many Languages Resources

<http://nnlm.gov/outreach/consumer/multi.html>

Extensive list of links to health information in various languages, arranged by languages. The list is searchable and consists mostly of information directories.

NOAH

(New York Online Access to Health/Acceso Computerizado de la Salud en Nueva York)

<http://www.noah-health.org/>

NOAH is a portal to a vast amount of full-text consumer health information, some onsite and some external. Most materials are in English and Spanish, with other languages represented here and there. The site itself has an English version and a Spanish version. The NOAH Content Committee is responsible for selecting and approving topics and links. NOAH's criteria for inclusion are as follows:

- Author institutions and/or names are clearly displayed on the linked page.
- Links are selected to provide balanced and unbiased information on a topic.
- NOAH does not endorse or represent any commercial venture. Links that contain advertising are chosen solely for their informational content.
- Information on the linked pages is current.
- Every effort is made to select content that is clear and understandable.

NSW Multicultural Health Communication Service

<http://www.mhcs.health.nsw.gov.au/>

This agency of the New South Wales, Australia government provides translation service, information and advice, research services, and communication services. Its web site contains hundreds of translated consumer health brochures in dozens of languages, translated by the agency. Most listings include an English version of the item in question.

Spiral

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<http://spiral.tufts.edu/>

A joint project of South Cove Community Health Center and Tufts University Hirsh Health Sciences Library and supported by a grant from the New England Region of the National Network of Libraries of Medicine, Spiral provides health information in seven Asian languages. Subjects Spiral is most rich in include cancer, senior health, and children's health, among others. The site itself is available in all seven languages it addresses.

Networks

Community-Campus Partnerships for Health

<http://depts.washington.edu/ccph/index.html>

CCPH is a non-profit working to increase collaboration between academic institutions and communities, now comprising over 1500 communities and campus around North America and beyond, promoting health through service-learning, community-based participatory research, broad-based coalitions and other partnership strategies. Goals include building capacity of communities and higher educational institutions to engage each other as partners, incorporating service-learning as a core component of the curriculum in colleges and universities, recognizing and rewarding community-based teaching, research and service, and developing partnerships that balance power and share resources. Academic institutions and grassroots community groups can find themselves at odds with each other as communities see funding going to big campus departments and institutes based in part on established and scholarly reputations, while community-based groups who know their communities' needs and have practical ideas for solving problems miss out. Combining the resources of both camps is good news.

MedlinePlus Go Local

<http://www.nlm.nih.gov/medlineplus/golocal/index.html>

Another National Libraries of Medicine project, GoLocal is a nationwide directory of health resources by state and a few otherwise defined regions such as the Four Corners area and manageable chunks of Texas, including hospitals, physicians, nursing homes, support groups, health screening providers and many others. The NLM contracts with a regional medical library or other institution to produce and maintain listings in each state or region. Currently, some states have basic coverage listing hospitals only, while 21 others have "complete" GoLocal coverage. "Complete" coverage is probably not truly complete, but listings for those states are remarkably rich. "Basic" coverage areas are those that do not yet have a regional contractor. GoLocal is integrated with the MedlinePlus site—MedlinePlus links users to local resources via GoLocal, and GoLocal links users to MedlinePlus's health information.

National Network of Libraries of Medicine and the United States National Library of Medicine

<http://nml.gov>

<http://www.nlm.nih.gov/>

National Network of Libraries of Medicine Pacific Northwest Region

<http://nml.gov/pnr/>

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The mission of the National Network of Libraries of Medicine is “to advance the progress of medicine and improve the public health by providing all U.S. health professionals with equal access to biomedical information and improving the public's access to information to enable them to make informed decisions about their health.” Many if not most medical libraries in the United States, whether in hospital, academic, or non-traditional settings, belong to the network. Members are supported via eight regional offices under contract with the National Library of Medicine. Washington State falls within the National Network of Libraries of Medicine Pacific Northwest Region (NN/LM PNR) which includes Washington, Oregon, Idaho, Montana, and Alaska. The NN/LM PNR office is located at the Health Sciences Library at the University of Washington. In the NN/LM context, the UW Health Sciences Library is referred to as the Regional Medical Library or RML.

National Network of Libraries of Medicine as a funder of health information outreach

The National Network of Libraries of Medicine (NN/LM) provides grants for health information outreach projects on a regular basis.

NN/LM PNR is particularly interested in health information outreach projects to underserved populations in its administrative region. Many funded projects have increased the ability of local public libraries to serve the health information needs of local communities in rural areas and small cities and town. These projects often involve collaboration with local community organizations. [information about local public libraries’ role as health info sources for small and isolated communities]

NN/LM PNR provides several categories of funding, including \$500 training and exhibition grants, \$2000 planning and assessment grants, and \$12,000 express outreach grants. NN/LM PNR’s funding application process is refreshingly simple and fast compared with many funders, as the office knows that staff members of small organizations, hospitals, and libraries don’t have time to waste on proposals that may or may not be fruitful. In addition, NN/LM funding is easy to secure, with the ratio of applicants to recipients being quite favorable. The network looks for innovative, non-traditional projects amongst its funding applicants.

In addition to funding, NN/LM PNR provides support and guidance to its contractors and prospective applicants throughout the process, and its web and publications resources are available to anyone. NN/LM PNR’s publication *Measuring the Difference: Guide to Planning and Evaluating Health Information Outreach* is particularly helpful.

A few projects recently funded by NN/LM PNR:

Web-Based Immunization Information Resource Library Project

Healthy Roads Media

Bozeman, MT

Period of Performance: January 1, 2007 - March 31, 2008

This project will involve the development of English and Spanish written vaccine information statements (VIS) that cover most of the common children and adult immunizations (Chickenpox, DPaT, Hepatitis A, Hepatitis B, Hib,

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MMR, Inactivated Influenza, Pneumococcal polysaccharide, Td, and Polio) into enhanced formats. These enhanced formats include audio, multimedia, and web-based video. In addition to the full content versions of the VIS materials, shortened versions that cover key concepts about each vaccine will be developed. These shortened versions are anticipated to be particularly useful in busy clinical settings where a short patient education presentation (less than 5 minutes) is more practical than the 10-15 minutes that the full versions will typically run. All materials (in addition to the written format) will be made available on the web. Formal evaluation of the materials will be done in immunization clinics at the local public health department (Gallatin City-County Health Department, MT). Training of staff will be carried out in the clinical evaluation site(s). Evaluation of the effectiveness of the web dissemination will also be carried out.

Tacoma Hilltop Health Outreach 2007

Allen Renaissance, Inc.

Tacoma, WA

Period of Performance: January 8, 2007 - January 31, 2008

This project will provide community outreach health education for residents of the Hilltop community in Tacoma, Washington, a predominately African American Community with many underserved, low income and senior residents. The Health Coalition for Communities of Color (HC3) has provided health education programs in the Hilltop since 2004. Allen Renaissance, Inc. (ARI), a 501 (c) (3) arm of Allen AME church offers community outreach services on the Hilltop and has a history of collaboration with HC3 in delivering these community health education programs. The partnership, between ARI and HC3, will continue to expand and will begin to offer services on a monthly basis, to include training session health education that covers from birth to death issues and training to community leaders for ongoing health prevention models. These services will improve the health and quality of life for residents of the Tacoma Hilltop.

The contact person for outreach grants is the very helpful, dedicated, and enthusiastic Linda Milgrom.

Refugee Health Information Network

The Refugee Health Information Network (RHIN, <http://www.rhin.org/>), based in Arlington, Virginia at the Center for Public Service Communications (a consulting firm), and Georgetown University, is a national collaborative partnership that has created a database and portal of health information in multiple languages for patients, refugee health information for providers, and information about health services for refugees and immigrants. It is also intended to function as a forum for programs to share their stories and learn from each other.

RHIN's beginnings date to at least 2002. In 2003 the Robert Wood Johnson Foundation provided funds for two meetings. Refugee health coordinators from health departments in Texas, Illinois, and Massachusetts met with John C. Scott of the Center for Public Service Communications to discuss ways to gather and share information about refugee and immigrant health. They proposed creating a network of individuals and agencies providing health care to refugees and immigrants, with a central, publicly accessible web-based database at its core. Recommendations from the first meeting are as follows:

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- **Establish a central repository of culturally and linguistically appropriate health information.** Participants endorsed the concept of a national, Web-based database of the materials with a coordinating/managing agency.
- **Create standards for translation and assessing and developing multilingual and multicultural materials.**
- **Coordinate efforts to develop appropriate health information for refugees and immigrants to avoid duplication of efforts and ensure high-quality materials.**
- **Reach out to health care providers, community organizations and refugees and immigrants so they are aware of available information.**
- **Develop an infrastructure to sustain funding and support for continued development and dissemination of culturally and linguistically appropriate health information.**

Under Project Director John C. Scott, with technical support from the Imaging Science and Information Systems Center at Georgetown and funding from the National Library of Medicine, the workgroup developed a prototype web site. Sixty people attended the second meeting, comprising coordinators of immigrant/refugee health divisions of state and county health departments in seven states, professionals in language interpretation, web site development specialists, immigrant and refugee health care providers, and disaster experts. The following recommendations resulted:

- **Ensure that the Refugee Health Information Network will be sustained.**
 - Expand network partnerships, particularly with state health departments.
 - Prepare a strategic/business plan.
 - Secure funding through sources possibly including the U.S. departments of Defense and Homeland Security.
- **Create a user-friendly Web site.**
 - Identify the Web site's audience, possibly to include both providers and consumers *via* different sections of the site.
 - Design the Web site to be easy to use, including a clear and attractive home page, easy pathways for searching and easily retrievable and readable documents.
 - Create a means for Web site users to interact with one another, particularly for the purpose of providing comments to developers of materials.
 - Expand the "Frequently Asked Questions" section of the Web site.
- **Maintain a high quality of information on the Web site.**
 - Ensure the selection of high-quality resources through development of criteria for selecting materials and determining quality.
 - Ensure that Web site resources are kept current by developing indicators for what materials need to be updated and when. Include dates when materials were last reviewed or updated.
 - Promote the development of high-quality resources and offer tools to help develop such materials. Identify best practices/standards/criteria for developing resources.
 - Include easily accessible English translations.
 - Provide information on the Web site about how each resource was developed and evaluated.

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- Include information on the Web site about copyrights. Consider seeking attorney advice on copyright issues.¹³

After the NLM's funding to Georgetown and the Center for Public Services Communication ended, private firm Lockheed-Martin took over development and design of the web site. The Center for Public Service Communications continues to manage RHIN.

The latest version of RHIN was unveiled in April 2007. Member organizations submit materials for approval and inclusion on a volunteer basis. RHIN has specific guidelines and policies in an effort to ensure the quality and currency of available materials.

The prominent focus on refugees resulted from Federal funding priorities, but RHIN's usefulness is not limited to the foreign born and those who work with them, and the scope of materials goes beyond refugee information. Nevertheless RHIN's database and search interface are far from ideally extensive as of June 2007. Its patient education materials can be selected by at least 79 languages, but there are no options to search for easy-to-read materials or English-language materials developed for specific communities. In addition, RHIN has not been consistently responsive to inquiries.

National Partnership for Cultural Competence in Health Care

Under Director Dennis Andrulis, the Center for Health Equality (CHE) at Drexel University received a grant from the W.K. Kellogg Foundation to "assess the feasibility and value of, and develop a plan for creating a national organization to address racial and ethnic disparities in health and improve cultural competence in health care. Among its activities under this grant, CHE is: (1) conducting a comprehensive review of organizations, foundations, private-sector and government-sponsored initiatives aimed at cultural competence in health care and the reduction of health disparities; and (2) interviewing community leaders, experts, government officials and individuals from leading national organizations to seek their guidance and determine their willingness to participate in such a partnership."¹⁴ The project has subsequently received funding from the U.S. Department of Health and Human Services Office of Minority Health to create a national resource center and clearinghouse on racial and ethnic diversity and health. Among other activities, Andrulis has collaborated extensively with DiversityRx (<http://www.diversityrx.org>) and its parent organization Resources for Cross Cultural Health Care, and others in organizing the biennial National Conference Series on Quality Health Care for Culturally Diverse Populations.

Currently, Drexel's resource center project is listed on CHE's web site as the National Partnership for Cultural Competence in Health Care. How this will develop remains to be seen but if successful it stands to be a major player in networking, training, and other resources related to culturally and linguistically appropriate care.

¹³ Information on RHIN's process derived directly from Robert Wood Johnson Foundation. "Recommend Web-Based Information Network to Improve Health Care of Refugees and Immigrants—Grant results." Princeton, NJ: RWJF, last update 2007 <http://www.rwjf.org/reports/grr/053555.htm>.

¹⁴ Center for Health Equality at Drexel School of Public Health. "Current projects." Philadelphia: CHE, 2006-2007. http://publichealth.drexel.edu/che/Current_Projects/35/

Federal agencies

Agency for Healthcare Research and Quality (AHRQ)

<http://www.ahrq.gov/>

The Agency for Healthcare Research and Quality (AHRQ) is the lead Federal agency charged with improving the quality, safety, efficiency, and effectiveness of health care for all Americans. As one of 12 agencies within the Department of Health and Human Services, AHRQ supports health services research that will improve the quality of health care and promote evidence-based decision-making.¹⁵

As the Federal health quality assurance agency, AHRQ could potentially handle quality control functions and guidelines for a national network for culturally and linguistically appropriate health information.

Centers for Disease Control and Prevention (CDC)

<http://www.cdc.gov/>

CDC Minority Health

<http://www.cdc.gov/omhd/Topic/MinorityHealth.html>

Addressing health disparities is one focus of the CDC's strategic plan. The CDC has several programs related to culturally and linguistically appropriate care. The Minority Health Statistics Grant Program was established to fill in gaps in minority health data, necessary knowledge for public health. Healthy Youth! funds local and state agencies and nongovernmental organizations to implement strategies to reduce disparities among populations that may be disproportionately affected by health-related risks and problems.

Office of Minority Health, U.S. Department of Health & Human Services

<http://www.omhrc.gov/>

Among other activities, this office is responsible for the CLAS (Culturally and Linguistically Appropriate Services) standards, funds local projects, and houses the OMH Resource Center. The OMH Resource Center (OMHRC) features a database of programs, newsletters, current awareness alert services, and information reference service. The OMH site features key resources for understanding and implementing CLAS. The OMHRC represents another possible host for a national infrastructure.

Professional Associations

Medical Libraries Association

<http://www.mlanet.org/>

North American professional association for medical libraries and librarians. Plenty of professional resources.

¹⁵ Agency for Healthcare Research and Quality. *Agency for Healthcare Research and Quality (AHRQ) At A Glance*. AHRQ Publication No. 06-P003-1. Rockville, MD: AHRQ, 2005. <http://www.ahrq.gov/about/ataglance.htm>

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American Public Health Association and APHA Health Disparities Database

<http://www.apha.org/>

<http://www.apha.org/programs/disparitiesdb/>

The American Public Health Association's database collects information on programs addressing health disparities across North America. Users can search by keyword or check one or more boxes representing specific populations, age groups, and basic program descriptions. APHA also publishes the high quality *American Journal of Public Health* and a fine set of disparities factsheets.

Society for Public Health Educators (SOPHE)

<http://www.sophe.org/>

"SOPHE is an independent, international professional association made up of a diverse membership of health education professionals and students. The Society promotes healthy behaviors, healthy communities, and healthy environments through its membership, its network of local chapters, and its numerous partnerships with other organizations. With its primary focus on public health education, SOPHE provides leadership through a code of ethics, standard for professional preparation, research, and practice; professional development; and public outreach."¹⁶ With its role in health education and promotion, SOPHE may have a role to play in familiarizing health educators and health promoters with the need for culturally and linguistically appropriate care and providing guidance and resources.

¹⁶ "About SOPHE—Snapshot—Mission/Values statement." Washington, DC: SOPHE, 2005.
http://www.sophe.org/content/mission_statement.asp

Appendices

Appendix 1: Condensed focus group and interview comments

A total of nine individuals participated in either a focus group or individual interview. Both settings utilized the same questions. All participants are involved in work that aims to improve access to care for underserved communities, such as interpreter services, training of service providers, community outreach, and culturally and linguistically appropriate health promotion/patient education materials.

Note: In the following text regarding focus group and interview outcomes, “I” refers to the speaker, not the present author.

1. Please introduce yourself and give a brief synopsis of your work as related to culturally and linguistically appropriate health information.

- Educator with CHILD Profile (Washington State Department of Health), which produces immunization info and tracks WA kids through age 6 in an effort to ensure consistent immunization. CHILD Profile’s general information is available in English and Spanish, but specific immunization information is available in 15-20 languages
- Training manager with Minority Executive Directors Coalition. Does cultural competency and anti-racism training for other organizations. Formerly health educator and program manager with Cross Cultural Health Care Program’s Health and Nutrition Demonstration Project which developed culturally and linguistically appropriate programming for people with or at risk for chronic conditions such as obesity, diabetes, hypertension and heart disease, in the Pacific Islander, American Indian and Alaska Native, Filipino, Hmong and Mien communities.
- Academic health librarian, liaison to UW Medical Center. Assesses providers’ needs for patient education material. Contributor to Culture Clues 11 ethnic community profiles, which included collaboration of cultural informants in process, plus developing end of life profiles.
- Health educator in health promotion at DOH, administrator of H.E.R.E. database of Washington programs and materials in health promotion. Monitors quality of materials and programs. Includes repository of translated documents. H.E.R.E is funded and being overhauled currently.

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- National Network of Libraries of Medicine Pacific Northwest Region Outreach Coordinator. Does little direct work with CLAHJ except for some passed-along reference questions. As Outreach Coordinator, helps approve and distribute funds to health information outreach projects around the northwest.
- Interpreter services manager for Swedish Hospital. Serves on patients and physicians committees. Experience in process control, optimizing efficiency.
- Librarian, Health Education Coordinator, National Network of Libraries of Medicine Pacific Northwest Region. Role includes working with intermediaries from underserved communities to distribute health information
- Librarian, Harborview Medical Center and creator and manager of Ethnomed.org, which provides culturally and linguistically appropriate health information for providers and patients.
- Librarian at Public Health – Seattle & King County, manages digital public health library; she was passed a long-time Public Health project that collects and evaluates health promotion materials. The collection is now on the H.E.R.E. database at the State. Public Health is not currently reviewing materials for that collection.

2. Please describe the ideal information system for culturally and linguistically appropriate health information. What qualities should it have?

User friendliness and accessibility:

- I want to push a button and get whatever I want. If a CD or radio broadcast can be like that, instantly and on demand. If we can have Comcast on demand we should have access to information
- On providers' desktops; easily accessible
- Should be online and accessible to people
- It should be simple, accessible, and at the places where people go.
- barbershops
- faith communities
- There is information overload, how to access what you need without an excess and overlapping

Cultural competency

Developing culturally and linguistic information:

- no two programs can or should be alike, because every group is different and you have to build a relationship with a community
- people have different learning styles, need to have people who are prepared to work with different learning styles

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- figure out what is important to the audience—it may not be what you think
- materials should be developed for an audience, rather than just translating everything
- Standards of quality assurance—guidelines for what’s on it, explanation of approval process
- Guidelines for assessment of cultural appropriateness
- Readability/reading level should be addressed
- Identify needs based on community, not public health workers
- Not just non-English; readable information is needed by all of us under stress. Medical language is its own non-English language
- Western medicine is tied to very linear English language materials; linear approach not always appropriate
- Sometimes a family member can use the material even if the patient can’t—it may take a family member to use the DVD player or computer and follow medical instructions, so can’t assume because patient is LEP or unfamiliar with formats that it will not be used. Think of target audience beyond the patient. Relatives often help in decisionmaking
- Must have community buy-in, community champions who advocate for it
- Cultural appropriateness requires community review—example, a brochure telling parents that nothing should be in the bed with the baby, when in reality, people from many cultures routinely put lots of things in bed with the baby including parents sleeping with babies

Formats

- should be in multiple formats—many people aren’t literate in their own native language
- Should be written and oral, should speak to both oral and written characteristics of subgroups of cultures such as Latino population
- Need an oral system
- Technology like that used for video interpreting—can see the person on each end
- Pictorial
- Translate/adapt MedlinePlus tutorials; a few have been done such as Vietnamese breast cancer
- Also hearing disabilities
- Materials should not have too many words and not enough pictures
- Include video materials

Logistics

- Systematic system with defined roles for participants in order to gather, review, and disseminate
- Ability to identify holes
- Identify overlap

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- Avoid redundancy
- Develop at local level with trusted sources, gather at state level for centralization, and feed into national resource like RHIN
- Because I'm a librarian I worry about how authoritative things are. We often get requests from people who do not speak the language of the patient they are looking for the materials for. I think there should be one-to-one translation. If you do not speak the language or are not familiar with the culture I can't see how you can be sure that this pamphlet is about diabetes and it's in Hmong therefore it's good for my patient. They have to know exactly what the material says before they'd trust, I hope, giving it to a patient. A lot of materials we have no way to evaluate. Need some way to evaluate the content. Then there are all those librarian issues. Quality control issues—date, who produced, is it the most current edition on top of the other standard ways to evaluate
- For example RHIN has a policy where each item must be reviewed periodically every 2 years to see if it's still appropriate
- Need to keep ourselves up to date, need current awareness functions like RSS

3. What are some organizations and programs that you think are most successful in connecting service providers and members of the public with culturally and linguistically appropriate health information, and why?

(Listings are interview/focus group participants' suggestions)

- Ethnomed.org
- Spiral (<http://spiral.tufts.edu/>)
- 24 Languages Project (<http://library.med.utah.edu/24languages/>)
- NN/LM Consumer Health Information in Many Languages Resources (<http://nnlm.gov/outreach/consumer/multi.html>)
- Grant project we did at Children's [Seattle] with funding from NNLM for parents of children with special needs—in addition, a refugee organization replicated it for their community.
- Parent to Parent of New York (<http://www.parenttoparentnys.org/>)
- Linking community groups with public libraries
- Hospital libraries are learning to serve needs of patients in addition to providers. Highline's Planetree library, Children's Hospital's health resource center, Swedish's health resource center
- Local public libraries. Some are working hard on this, others are problematic, for example at one local library staff were unaware that the public can access PubMed.
- Cross Cultural Health Care Program's publications and work (<http://www.parenttoparentnys.org>)
- International Community Health Services in Seattle and similar groups working in local communities. ICHS is now serving East African and other communities in addition to Asians and Pacific Islanders. (<http://www.ichs.com/>)

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- Asian and Pacific Islander Women and Family Safety Center, which is sensitive to men's and children's needs in addition to women's. They are getting better and better. (<http://www.apiwfsc.org/apiwfsc/index.html>)
- Refugee Women's Alliance (ReWA) does very well though may be having growing pains as they serve a greater array of communities and hire people from an ever-increasing variety of backgrounds. (<http://www.rewa.org/>)
- Culture Clues from UW medical center. They are provided both online on the intranet and the UW Health Sciences Library's Healthlinks site but also various clinics in the center have laminated print versions. People were given rings with which to organize them, adding new ones to the rings as they become available. (<http://depts.washington.edu/pfes/cultureclues.html>)
- Ohio—they have one of the best I've seen is Ohio State. Totally seamless, all available. From patient to academic side. From what patients or providers want to look at, you almost didn't realize you were moving. Very intuitive, well done. I haven't seen much written from Ohio State.
- WIC (Women, Infants and Children Nutrition Program) has a well funded network and they encounter more LEP people than any other department at DOH. They do a good job staffing offices with people who speak various languages and they provide multilingual materials. (Washington's WIC program: <http://www.doh.wa.gov/cfh/WIC/>, National WIC Association: <http://www.nwica.org/>)
- Immunization programs such as CHILD Profile. CHILD Profile has produced materials in more languages than any other department at DOH. (<http://www.childprofile.org/>)
- Most of DOH is far behind these previous two. In places where they encounter people with limited English proficiency the most they have to come up with ways to appropriately serve people: hospital, schools, the legal system. It's easier to see progress with these kinds of subjects. We're trying to make a system for all DOH departments to help them figure out how to communicate well, consistently. Step by step, protocols, whatever we can do to make it easier for a program.
- National Network of Libraries of Medicine (NN/LM). We do not fund top heavy projects. The funding must go to the community. Programs must be community-based, we have to be convinced that enough members of that local population group are involved for the information to be trustworthy and broadly applied. (<http://nnlm.gov/>)
- **Culture & Clinical Care.** Edited by Juliene G. Lipson and Suzanne L. Dibble. UCSF Nursing Press. 2005.
- National Center for Farmworker Health (<http://www.ncfh.org/>)
- There's a group in California that took what we had done with multicultural diabetes at Harborview, really expanded on it.
- The National Cancer Institute (<http://www.cancer.gov/>)
- A Project of the National Cancer Institute and Harborview Medical Center

4. Quality control: Are there programs or techniques in existence that you think are particularly successful in ensuring the quality of materials and/or the programs that provide access to them?

Community input and review

- The processes employed in CCHCP in many of its publications such as *Voices of the Communities* and the later community profiles. The quality of the materials has been excellent, and insuring that the community gets to look and see what's being said is a vital part of that.
- Culture Clues project. There are now advisory councils in the medical center, service areas such as oncology, or maternal care, which have patient advisors from different cultures, patient family ed dept organizes advisors—what they say is taken very seriously. Their opinion is sought out. That acts as a quality control for sure.
- We follow a health education model, meaning we try to ideally get input from the audience before we write anything, learn their concerns and barriers to whatever we're trying to communicate, tailor it to their needs. Once something's developed it's tested using people from that target audience so info is clear understandable and compelling. Doesn't always happen but that's our model.
- What we're looking at is ensuring that translators and interpreters are certified and continue training, and some recognized way of knowing.
- It's really important to know what the audiences needs and wants, not us telling them what they need to know but figuring out the best way to communicate.

Other

- MedlinePlus—they have a Spanish language interface but if you don't speak Spanish you won't start there. I appreciate that there are unique materials to both the Spanish and English language versions. When there is an actual verbatim translation, when I can read in English exactly the content to be delivered in Spanish, that is noted on the site. They note "also available in Spanish" or English. BUT for example if somebody says "this is a great pamphlet on disease x in Portuguese, if I don't speak Portuguese I can't trust it, I need to know what it says.
- We were trying to develop short videos demonstrating medical procedures in the emergency room for the purpose of teaching. We didn't want to do all of this if someone else had already done it. Even when we found that for example the American College of Surgeons had already made a video on a particular subject, we could not convince practitioners at Harborview to use these because it wasn't exactly, exactly the way they want to teach it at Harborview. Their versions of the procedures were slightly different, or they used a different brand of catheter or something like that so those existing resources weren't satisfactory to the doctors here. So we had to make original videos after all. It seems like a money waste, and I'm afraid that will happen with translations

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- I like to think that NNLM is very careful and have a quality control handle on what they do, what shows up on their website and in print. Other organizations may not have the limitations they have, say, being limited by the strictures of evidence-based medicine.
- Inventory systems can keep outdated materials in distribution because they won't make a new one until the old one runs out
- When health information first went online, I used to see the HONcode logo (Health Online Code of Ethics. It was an industry- and community-wide recognition that there was a need for quality control and ethical standards...it was like the Good Housekeeping Seal of Approval. I haven't seen it recently or not as frequently as I used to but that may be because I'm going to different web sites. There was a strong effort years ago to have that kind of code of ethics for health information sites and I don't know if that has persisted or not because it's a tough thing to enforce. That kind of effort is useful but how practical it is another question.
- Refugee Health Information Network (RHIN), which is a work in progress, has a review process for submission and materials must be periodically reviewed to determine if they should be retained.

Organizations named as examples of having good quality control but for which the participant didn't elaborate on their methods

- Public Health group in Minneapolis
- Ohio state stuff
- Pfizer
- Kaiser Permanente
- There was a great Canadian one but it's now defunct

5. Briefly, what subject areas and languages do you think are the best covered and most available, and what are some subjects and languages for which it is most difficult to find quality materials?

- e. Subjects with lots available:
- Immunization. In some states they have materials in 15-20 languages .
 - Diabetes
 - Heart disease
 - Obesity
 - Nutrition
 - Physical activity
 - Common conditions
 - Materials with the most demand for volume are made first
 - Women and Infant and newborn info
 - Emergency preparedness and homeland security, because it is a big priority with the government right now. Ten years ago it was STDs

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- Cancer
- f. Languages with lots available:
 - Spanish. Some of Medline plus and some of Micromedex are in Spanish
 - Russian
 - Vietnamese
 - Refugee and immigrant groups locally (Seattle area) covered by Ethnomed
- g. Subjects in need:
 - Rare disorders
 - Autism/Aspbergers spectrum
 - Birth defects
 - Genetic diseases
 - forms
- h. Languages or cultural groups in need of more materials:
 - Russian. Asian languages (Chinese, Vietnamese) used to be our core languages, now it is Russian that there is much need but little material
 - Vietnamese
 - Chinese (there are multiple dialects but most can read the same writing)
 - Many new Chinese immigrants are illiterate in their own languages
 - Toisanese/Hosianese/Taishan—a village Chinese dialect from Guangdong spoken by many older immigrants who've been in the US for decades. Can even be distinct within a community like Chinatown. (Alison Pence). There is no standard written system for this language; although Chinese characters are used, there is not a character for everything in Toisanese. There is no standard Romanization system either (Wikipedia http://en.wikipedia.org/wiki/Taishan_dialect)
 - American Indian and Alaska Native communities
 - Hearing impaired
 - New immigrant groups have to be assessed to find their specific needs
 - Micronesian languages are hard to find
 - Somali
 - African languages and dialects
 - Eastern European languages
 - South Asian languages that are not common in Seattle but may be encountered by providers in Washington because they are common just north in Canada
 - For many people, their first, second or third language are all languages we've never heard of

6. What are some proprietary and copyright issues affecting widespread access to culturally and linguistically appropriate health materials? If your organization produces such materials, are they available to the general public and if not, why not?

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We prefer to use information that is in the public domain/we produce materials for the public domain

- A lot of stuff is in the public domain.
- I try to steer people toward public domain info
- Ours is in public domain and is distributed in print, on line, and in volume. We have many people accessing them online.
- Children's makes an effort to get their information out
- No, ours are not available to the public; reasons include because they are very specific to medical procedures and they are not intended for lay people who might misuse them. There is a fear of liability and misinterpretation. Only our culture clues materials are available to the public, but you don't need a health professional to use them
- It's not an issue for us because with state and federal funding the materials are in the public domain. I advise organizations that if they receive federal money for something then they can't copyright it. We distribute our materials widely
- Not sure, but we point people to public domain materials like MedlinePlus which is placed there to be copied and distributed as much as possible.
- If they are producing something with outside support, they should be REQUIRED to make it freely available
- The Regional Medical Library and NN/LM intends its materials to be shared
- A lot of the materials we use for patient education we try to get from outside sources but we do produce some of our own, and I don't know about any kind of protection because it's open to the public.

Copyright

- I try to remind people to respect copyright, as in their zeal to share information people sometimes ignore it.
- Hospitals may not want to make information available to competitors
- One of the biggest difficulties for producing stuff to make available is the use of pictures. Digital protections in general can be so fuzzy you're afraid to use it even...Sometimes you can buy the rights [to an image] or it will be stated clearly "This picture can be used for this purpose". Getting permission can take weeks. When you're doing these projects every day you don't have time to do this for everything; you can do it for one thing but not everything.

Medical concerns

- They have this disclaimer saying this is not meant for diagnosing yourself, consult with your doctor. There are so many things you shouldn't be relying on these for...You end up having so many disclaimers on it it becomes almost tedious. I think that's probably the issue more than copyright.

Ambiguity

- Re: Children's Hospital: I know when I looked at their website they listed a bunch of them, and then it wasn't up to date and then I found some on their web site but I'm not sure if everything they use is there. And now they're starting to do diversity stuff and take it seriously.
- A lot of our materials we just hand out there or at the unit level. So if it's being handed out I'm not aware of any rights on it.
- What you have to worry about is if it's something that's produced by an individual, for instance there are presentation materials that are really good, produced by a physician, you might have to worry about stuff like that, you hand it out but that doesn't mean then you can reproduce it. That's the grey zone. I went to one of those talks and asked if they could print me a copy and they were like "well we're not sure if the physician who gave the presentation would ok it".
- But you know with information, so much of it overlaps so how can you say that this sentence is mine? People just phrase it differently, a lot of what could be proprietary is your analysis or your recommendations but other than that, something you put in your report ...a lot of the work that goes behind that analysis and recommendation is public information.

Other reasons to share or not share

- Some things made by the UW are available to the public and some are not. Some are available only to the UW Medical center community. All of Ethnomed is available. With some pharmacy, they are trying to figure out how to make things available privately and publicly. It's not that they don't want to make it available, they just haven't figured it out yet. But that's not a policy barrier, it's a technology barrier.
- 7. What infrastructures exist in Washington State that could be better utilized and appropriately utilized to improve access to culturally and linguistically appropriate health materials, and how? (For example, the State Library, National Network of Libraries of Medicine/Pacific Northwest Region, WA Department of Health)**
- a. What are some pros and cons of these infrastructures?**
 - b. How about national and international infrastructures? (For example, Refugee Health Information Network, National Library of Medicine)**

Libraries

- Public libraries are where some of these individuals would actually show up, or community resource centers are places where people show up. Public library is a remarkable infrastructure that can be utilized better. Sadly, KCLS no longer has a health librarian

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- NNLM has great role in funding these projects. With our project we reached many public librarians who were educated about community groups in their community and a health information need in their community
- Don't know how State Library could play role, already reduced
- Regional libraries are very available accessible. Spanish speakers use them a lot. Timberland libraries have Spanish outreach program
- NNLM system is great for people who understand it
- The state library mostly backs up public libraries and I know public libraries get health questions but I don't know how many would involve culturally and linguistically appropriate health information, if non-English speakers are comfortable going in there
- Seattle Public Library has never been involved in this, I've tried contacting them in the past. Very odd.

Washington State Department of Health

- DOH works really hard on specific projects.
- I connected but not really with HERE in Washington
- Eliz. Comstock's stuff is connected with HERE but I don't really understand how that played out and I think if I can't understand it, how can somebody else take advantage of this program.
- DOH programs touching LEP could be better utilized by WIC
- State DOH. It is in touch with local health departments who have lots of newsletters and potential for getting stuff out. May be appropriate partners
- DOH pairing with State Library could be a very powerful pair and I think that HERE was going in the right direction they just needed more support. But state library has been very scaled back
- HERE is completely revamping web site

Existing large entities need to connect meaningfully with communities

- These entities naming here need to figure out how to connect locally with local organizations that meet the needs of these community groups to get info where you'd like it to be.
- Get infrastructure to reach into communities to grass roots groups, church groups, public libraries, places people go into community
- There's a Consumer Health Information Advisory Group the network has, which I'm on, in the PNR region. They do a wonderful job but it's challenging for them to make a strong local connection with some of their projects.
- From what I've seen many of the infrastructures are utilized mainly by people who know about them, it's very difficult without the proper funding. When you have orgs on the grassroots level you need just as much if not more funding to give to these

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organizations who really know the people they serve. Even people like me, and I consider myself educated, I'm not sure where to go to access the materials that may or may not be out there.

- Obviously a great project for the Go Local project of RMLs, also MedlinePlus. That one RML has done a great job of getting it started.

Reasons grassroots organizations may not be reaching out to each other and to larger infrastructures

- You need to be vocal about your community's needs but every community has different needs and styles and convention, for example in Japan, "The quacking duck gets shot", not "The squeaky wheel gets grease". Need to think of this when encouraging people to ask for what they want and what they bring to the table
- And there are people who for whatever reason some people don't want to share. They want to hoard that information for themselves. It still goes back to oppression issues. People feel that they need to hoard as much of this information as they can to get ahead. We need to change the mindset of people but it's really hard because it's been ingrained for so long. Need to educate people about oppression and about undoing institutional racism in order to reverse this

Refugee Health Information Network (RHIN)

- RHIN needs big influx of funding for promotion and development, I don't know how far they can go as volunteer efforts. NLM is interested, has manpower, connections, credibility in health and library community
- I have mixed feelings about [national infrastructures]. It's hard to maintain those things. RHIN—I think problem with national resources is they can't focus on local needs. Very big differences across country with dialects or language. Something Spanish from New Jersey may not work for. WA Spanish speakers. Role of national is to fund local not so much to do the information
- RHIN is trying to be international and provide materials from other countries.

Special interest groups

- Special interest groups at state and national level such as National Hispanic Institute on Aging
- Society for Health Education, SOPHE is a better fit than libraries. Libraries are not the first natural partner. An umbrella group like SOPHE is more appropriate. Margo Harris, active member of SOPHE and real library champion. Interpreters are more connected to SOPHE and providers than to librarians

Local infrastructures

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- Seattle Department of Information Technology, Community Technology is a great model. It gets people working together in reasonable way. David Keys. Created center for people with communication issues. They know the latest technology. ESL focus and vocational stuff. East African communities and others. They've worked with us Ethnomed
- Community colleges
- CHOICE Regional Health Network
- Don't know the quality of materials. UW Medical Center has many direct translations but you don't know if they are culturally sensitive and they probably aren't.

Other

- Faith-based orgs
- Listservs. But this is mostly librarians and people in community organizations who've thought to join our network. I don't think --that directly that's a way to get people who are intermediaries, who receive the questions to know about places to go. Certainly we want to publicize and have a blog and do a newsletter but I'm not sure that the practitioners and people who need the materials are likely to come to us.
- AHRQ could underwrite guidelines, clearinghouse, quality measures

Commentary

- But in rural areas, where do the patient educators and discharge people go to get information that would be appropriate to hand to patient at time of leaving or outpatients.
- Microsoft does terrible translations, and so do localization companies. Need standards.
- Infrastructures are not designed for general public but for local organizations, planned parenthood, etc. Any org, such as WIC, focuses on its own interests. People need direct learning, community health worker model

8. What standards and conventions should be utilized or adhered to in organizing culturally and linguistically appropriate health information? In producing information?

Specific standards and techniques

- I think a big step was made with the CLAS Standards. However I'd like to see the rest of the CLAS standards be mandated. Getting rest mandated would be better
- Testing of certification of translators and interpreter is very important and so is testing materials with intended audience.

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- SOPHE and health educators may have something
- Especially with the non-Roman scripts it would be nice to use a standard format but how can you influence that, how can you tell someone in a small place that he can't use what is most convenient and available at the time.
- People are going off in different directions with standards, like the intelligence community. Collaboration is easier said than done. Being myopic, you can only do what fulfills the goals of your company.
- Health on the Net Foundation: Information You Can Trust (not government, which I think is a plus).
- With health information and medical information you do have to have some kind of medical accuracy review process in place and if you don't get accredited by HONCode you should at least be aware of their principles and follow their or similar principles regarding health info.
- Maybe standards for things being submitted to something like RHIN, but there are trade-offs
- Must be up-to-date and not retain outdated information
- Sometimes these on-the-spot-produced, casual things are better and more appropriate but you have less control because they aren't submitting to a clearinghouse and if they are, who updates? If submitted, they forget they submitted it and don't have a sense of ownership and responsibility about following it and submitting updates.

Creating culturally competent materials

- If you have identified a culturally group you want to work with they must be represented at every step of the process.
- Redundancy and working with communities. Communities get mad and say why do communities keep going through this, why are you asking us again, and it happens over and over, it's really unfortunate.
- Can't just translate an item into different languages. One of the conventions needs to be that you will develop it in languages as it is needed and desired by that population. Must think beyond straight translation to developing materials for specific needs.
- Producers and system must be culturally competent and know their community's needs
- Consider language register and social class. Matching patients and interpreters of different social classes sometimes doesn't work.

Usability

- Needs to be simple for providers and patients to find. Otherwise they won't use it. It should be sort of in their face or it won't get used, like Ohio state
- Customizable from user's perspective.

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- 6th grade reading level
- Medline's interactive tutorials
- an English translation or summary, more than a summary, must be provided

9. What sectors or populations do you see as major stakeholders whose participation is necessary to provide and make high quality, culturally competent information accessible for service providers and the public? (examples: community leaders, community health workers, public libraries, clinic staff, educators)

Providers and health workers

- Community health workers
- Clinic staff
- Health educators
- Nursing staff
- Physicians
- Hospitals

Communities

- Community leaders
- Regular people from the communities
- Community group representation itself would be an expansion of the examples given.
- Everyone has a stake. Some people who might be seen as community leaders don't see themselves that way but they are. Regular people's perspective is as important as CEOs' And for all these people who come up with these big ideas, how many of them are just regular everyday common people and they probably have as good ideas as the big CEOs who get paid the big bucks. Maybe if we would listen to the common person maybe we wouldn't have the problems that we do now. We keep doing the same things over and over when it's already been proven that a lot of these things just don't work. So let's start listening to somebody else, give someone else chance because they probably know better.
- People from communities to review every item

Local government infrastructure and related agencies

- Local health departments
- Emergency preparedness people
- 211
- Firefighters
- Public libraries
- Educational institutions
- ESL programs. Use health as topic to learn English

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Related businesses

- Landlords
- Major employers
- Health insurers
- Graphic artists

International

- World Health Organization
- Other countries: Singapore, for example—people had lots of faith in the government regarding SARS. They provided really good outpatient information. There should be a good link to different cultures.
- We usually don't even consider international sources as viable. In other countries people think if it came from US it must be good; meanwhile Americans think the same thing and it doesn't occur to people in the US to check out international resources. They may do different things in different countries that work just as well as US medical techniques.
- Other countries using other languages have lots of good info but that's hard to get to if you don't speak the language.

Other

- I see three major groups: 1. Community and its leaders. 2. Practitioners distributing it to communities. 3. Librarians--less prominent but have much to offer [because of how this person expressed this, it is remaining intact rather than being distributed into other categories]
- Including graphics that customize for community

10. Who or what do you think should or could dedicate funding to developing, improving and sustaining these services?

Federal agencies

- There's commitment within local, state, fed government on this. I particularly like the focus on federal govt side to more readable, lower literacy materials. Govt agencies have a stake in that.
- Federal government
- NLM and RMLS
- NIH
- CDC

State and local agencies

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- State libraries
- NLM and RMLS
- Hospitals

Local organizations have the knowledge, large infrastructures have the means

- Local organizations know the community; federal organizations have the money
- Everyone collaborating lower down at state levels and then putting in a database maintained by one of these agencies, I don't care which, but they aren't carrying the full cost.

Special interest groups/related associations

- Related groups like American Lung Association

Commercial entities

- Pharmaceutical companies
- Think unconventionally. I went to the egg companies to seek funding for immunization work because one egg is required for each dose of flu vaccine.
- Specialty food companies

Large foundations

- Large foundations such as Gates and Allen should be contributing to work in their own backyard
- Kellogg, RWJ

Other

- Taxpayers

11. Is there anything else you would like to add or discuss?

- Tired of people denigrating earlier efforts based on what we know now—they were doing the best they could with what they have. I'm thrilled with progress made.
- People ignore those things and things will continue to be the same, and institutional racism continues to exist. We'll all continue to have our jobs, but it would be nice to be able to sit back and know your job is done.
- I think in public health there's a strong desire to do something but no guidance or resources. I think if there were clearer ways for people to apply what they know,

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- have contact ...if it was just easier to communicate their stuff in other languages and stuff there'd be a real willingness in pub health
- What are some existing barriers to wider access to appropriate health care information? Knowing where to look. I think if there were a single portal, well-known and well-trusted, it would be so much easier
 - As long as you can get stakeholders to realize they are stakeholder. Passing the buck. Where I'm from they call it Tai Chi (makes motion of pushing hands to the side). Federal—it's not a model that's going to work, look at their current administration, cares nothing about health
 - Process control. Look at it from process point of view Board of health should get a process control expert who can come up with something better. Different from strategic planning. Tighten all the inefficiency.

Appendix 2: Evaluating a Health Web Site

The following is content Evaluation Guidelines from the Medical Libraries Association <http://www.mlanet.org/>. These are a few things to keep in mind when viewing health information on the Internet.

1. Sponsorship

- Can you easily identify the site sponsor? Sponsorship is important because it helps establish the site as respected and dependable. Does the site list advisory board members or consultants? This may give you further insights on the credibility of information published on the site.
- The Web address itself can provide additional information about the nature of the site and the sponsor's intent.

A government agency has .gov in the address.

An educational institution is indicated by .edu in the address.

A professional organization such as a scientific or research society will be identified as .org. For example, the American Cancer Society's Website is <http://www.cancer.org/> .

Commercial sites identified by .com will most often identify the sponsor as a company, for example Merck & Co., the pharmaceutical firm.

- What should you know about .com health sites? Commercial sites may represent a specific company or be sponsored by a company using the Web for commercial reasons - to sell products. At the same time, many commercial Websites have valuable and credible information. Many hospitals have .com in their address. The site should fully disclose the sponsor of the site, including the identities of commercial and noncommercial organizations that have contributed funding, services, or material to the site.

2. Currency

- The site should be updated frequently. Health information changes constantly as new information is learned about diseases and treatments through research and patient care. Websites should reflect the most up-to-date information.
- The Website should be consistently available, with the date of the latest revision clearly posted. This usually appears at the bottom of the page.

3. Factual information

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- Information should be presented in a clear manner. It should be factual (not opinion) and capable of being verified from a primary information source such as the professional literature, abstracts, or links to other Web pages.
- Information represented as an opinion should be clearly stated and the source should be identified as a qualified professional or organization.

4. Audience

- The Website should clearly state whether the information is intended for the consumer or the health professional.

- Many health information Websites have two different areas - one for consumers, one for professionals. The design of the site should make selection of one area over the other clear to the user.

Appendix 3: Glossary

CLAS Standards: Standards for Culturally and Linguistically Appropriate Services

Culturally and linguistically appropriate health information/materials: Includes both culturally appropriate health info for patients and information for providers regarding communities. May apply to other materials too.

DOH H.E.R.E.: Washington State Department of Health H.E.R.E. in Washington, Health Education Resource Exchange

NN/LM: National Network of Libraries of Medicine

NN/LM PNR: National Network of Libraries of Medicine Pacific Northwest Region

NLM: National Library of Medicine

RHIN: Refugee Health Information Network

Appendix 4: Sources Cited

In addition to the following sources, the author read many other articles in preparation for this project.

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