

Reaching Out: Community Participation in Developing a Culturally Relevant Resource

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INTRODUCTION

Access to reliable health information is important for Indian people. The American Indian Health (AIH) Web portal (<http://americanindianhealth.nlm.nih.gov>) is unique, freely available, and dedicated to issues affecting the health and well-being of all North American Indians. This Web site is a collaborative effort between the National Library of Medicine (NLM), National Institutes of Health, and American Indians.

BACKGROUND

American Indian Health was developed in 2004 as part of the NLM plan to reduce health disparities including the lack of health information. American Indian Health aims to:

- ◆ Bring together authoritative health and medical resources in one Web site
- ◆ Include policies, consumer health information, research results, traditional healing resources, and links to other Federal and non-profit health initiatives for American Indians
- ◆ Be an inclusive source of programs and health information for both consumers and health professionals serving American Indians
- ◆ Present information from other NLM resources such as MEDLINE/PubMed and MedlinePlus®
- ◆ Be culturally relevant and easy to use

METHODS to IMPROVE and ENHANCE the PORTAL

- ◆ Expansion of the site's content is carried out through partnerships in the Native American community.
- ◆ Focus Groups:
 - 2005 and 2009
 - Teleconference and online
 - 2009 included consumers and health professionals
 - Transcripts provided feedback and impressions of the Web site
 - Can the site be used for patient education and finding current research?
 - Is the site easy to use and find information?
 - Is the information culturally relevant?
- ◆ User Group:
 - Organized in 2005
 - Managed by Indian owned reservation-based company
 - Coordinated by medical librarian
 - Spirit Lake Consulting adds oversight and cultural advisement for the user group
 - Members of the American Indian community work part-time
 - Share an interest in health information and commitment to improving the site for the betterment of all American Indians
 - Identify new resources, evaluate, promote, and make the Web site more responsive to the needs of users
 - Conducts online, teleconference, and in-person meetings
 - Suggestions discussed with NLM

RESULTS of PARTNERSHIP

- ◆ Additional Health Topics
- ◆ Redesign of Web site
- ◆ "Easy to Read" tags
- ◆ "Research and Tools" section specifically for health professionals
- ◆ Our Stories section:
 - Uses American Indian storytelling tradition to discuss personal stories from American Indians that relate to health topics
 - Identifies the importance of oral communication as a health communication tool
 - Idea was validated by both the consumers and health professionals focus groups
 - Plans for expansion by collecting and funding the creation of health stories in the American Indian community using various multimedia formats

CONCLUSIONS

The AIH information portal designed by NLM specially to meet the needs of American Indians has succeeded in making reliable and easily accessible health information available. Involving the communities served through user and focus groups has improved the efforts and enriched the Web site. As the site becomes better known throughout Indian country, it is the intent of NLM to continue to expand and grow the site to meet the needs of American Indians and assist them to better understand the health issues they face.

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

