



Consumer Health Information Request for Information (RFI) Request for Information (RFI) on Consumer Health Information Interests and Behaviors for Seeking and Using Health Information

Response Date: December 30, 2009

ISSUED BY

National Institutes of Health (NIH) Council of Public Representatives (COPR, <http://copr.nih.gov/>) and the Office of Communications and Public Liaison (OCPL), Office of the Director, NIH (<http://www.nih.gov/icd/od/ocpl/index.html>)

Requested Responses for Organizations and Health Care Providers

General Information

1. **Describe your organization's reach** (for example, local, regional, national). [Please use 100 words or less]

The Association of Academic Health Sciences Libraries (AAHSL) is composed of the directors of 116 libraries of accredited U.S. and Canadian medical schools, as well as 28 associate members. AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health practitioners is trained in information seeking skills that enhance the quality of healthcare delivery, including providing quality health information for consumers.

2. **Indicate your primary role** (for example leader of nonprofit health-related organization, clinician, physician, nurse, clinic or hospital staff, other allied health professional, professional caregiver, etc.). [Please use 10 words or less]

Health Sciences Librarian; President, Association of Academic Health Sciences Libraries

3. **Describe the services your organization or practice provides to its members/patients, including how you communicate with them.** [Please use 200 words or less]

AAHSL consists of the directors of academic health sciences libraries, who then communicate directly with their own constituencies. AAHSL has a robust website and active electronic communication channels that are used to easily and rapidly disseminate useful information to its members. AAHSL members work closely with health professionals and faculty in their institutions, providing yet another channel for distributing useful NIH consumer related information to those individuals to share with their patients. Some members provide information services directly to patients in their hospitals and clinics, and to their local communities. Increasingly, members work with their institutions to address global health issues as well.

4. **Indicate the languages your members/patients seek health information.** [Please use 20 words or less]

Primarily English and Spanish, but with rapidly increasing needs for other languages. Low literacy materials.

Health Information

NIH produces a large number of health, medical, and science education materials and resources on a wide variety of health topics for audiences that include patients, family members and caregivers, medical, health and policy professionals, legislatures, and media professionals. Your response to the question below will help NIH better understand what new topics health consumers seek and better tailor the information we disseminate.

1. **Please describe the health topics that are currently important to your members/ patients** (for example information on diseases, prevention, diagnosis, treatment, and health for women, men, teens, children, etc.) **Identify what language(s) the topics are requested.** [Please use 100 words or less]

AAHSL member libraries deal with the full range of health care professions and specialties at their large academic health centers, and consequently with patients and families of many different backgrounds and languages, with questions about a wide variety of topics such as Back Pain, Birth Control, Breast Cancer, COPD, Dementia, Diabetes, Diabetic Diet, Heart Disease, Herpes Simplex, High Blood Pressure, Hives, HPV, Kidney Diseases, Lupus, Multiple Sclerosis, Nutrition, Obesity, Ovarian Cancer, Parkinson's Disease, Pregnancy. In addition, many AAHSL libraries provide information services and resources to the general public, whether directly or through partnerships with public libraries.

Health Information Sources

NIH disseminates research advances to improve health and quality of life for all. Your responses to the questions below will help fulfill our mission to serve as a primary source of health information for consumers we may not be reaching and using sources ranging from community locations, to national organizations to new internet sources such as online forums, blogs, podcasts, social network sites, wikis and other social media.

1. Indicate how you think NIH should use the new Internet sources to send health information to your members/patients and describe the cases when NIH should use these sources ((for example, online forums, blogs, podcasts, social network sites, wikis). [Please use 200 words or less]

NIH is a trusted source of information and therefore should use all methods possible to reach its audiences. We encourage NIH to work closely with the National Library of Medicine (NLM) with its products such as MedlinePlus and Go Local, and emerging personal health record providers, and to take full advantage of the robust National Network of Libraries of Medicine to disseminate information broadly.

2. List ideas you have for NIH to distribute health information to specific audiences and indicate which audiences and how to reach them (for example local, regional, or national channels, print, online, in-person events). [Please use 200 words or less]

NIH and NLM need to promote their information services much more vigorously to compete with commercial (and potentially biased) sources of health information. The outlets would need to be tailored to different audiences. Examples are NPR with local connections to the other “commute-time” media. College newspapers which then provide opportunity for local connections. Even Billboards and Buses! Establishing effective promotional templates in multiple media formats would permit libraries and their community partners to adapt for their local populations. NIH and NLM need to create more of a “buzz” with their services to compete effectively with the “firehose” of information that we all face.

NIH Awareness and Role in Health Communications

NIH has a responsibility to communicate science-based, trustworthy public health and science information to a wide range of audiences, including the public at large, patients, family members, health care providers, scientists, public health workers, nonprofit health organizations, and professional societies. Your responses to the following questions will help us assess how familiar our audiences are with the agency’s efforts to provide health information.

1. Please describe your organization’s or practice’s understanding of the NIH’s role in (a) disseminating health information and (b) meeting the health information needs of the public. [Please use 200 words or less]

AAHSL members are very knowledgeable about the critical role of NIH in funding and disseminating both research information and consumer information, and we have a robust advocacy role in partnership with our sister organization, the Medical Library Association, that includes NIH and NLM funding as a top priority. AAHSL advocacy has also strongly supported the NIH Public Access Policy. Our members have served on numerous NIH and NLM advisory panels and extramural funding review groups, and have had an opportunity to shape the direction of information services and policy. We encourage NIH to continue to take advantage of this expertise and commitment.

2. Please describe how NIH can better communicate results of Federally-funded biomedical and behavioral research initiatives for maximum impact on the nation’s health, both within your organization or practice and directly to the wider public. [Please use 200 words or less]

Support meaningful partnerships between health sciences librarians and a wide variety of local service organizations and institutions to provide consumers, patients, and families with access to authoritative resources and services for informed health care decisions. For example, increased funding and visibility for outreach grants by the National Library of Medicine through the National Network of Libraries of Medicine could leverage the energy and talents of librarians around the nation,

and their knowledge of local populations. Because of the importance of global health, NIH should also collaborate with agencies such as WHO to make consumer health information more readily available around the world.

Open Response on Health Information

1. Describe any additional information you would like NIH to know about health information and/or health information resources. [Please use 300 words or less]

Health sciences librarians are a key component of health information access and literacy education. Opportunities exist for productive partnerships between health sciences librarians and librarians and staff in public libraries, public health departments, social service agencies, and community-based organizations to ensure universal consumer access to health and wellness information and health literacy education. AAHSL member libraries work closely with the National Library of Medicine in serving the public. The products and services of NLM (such as MedlinePlus, Go Local, the NIH MedlinePlus Magazine, and many specialized information services such as ToxTown) are essential to AAHSL member daily work. Additional resources to continue to build, support and enhance those services are critical. Investing in the National Network of Libraries of Medicine (with hundreds of skilled librarians around the country who are passionate about health literacy) would have a significant multiplier effect in helping to disseminate quality information from the NIH and other trusted sources.