

Summary of Research Activities by Key Approach and Resource

Health Communication and Information Campaigns and Clearinghouses

Norma knew she had some of the risk factors for heart disease—high cholesterol, age, and a family history. But it wasn't in her plan to sit around and wait for the worst. "I've had a lot of friends who have had heart attacks, and this has made me aware that I need to take care of myself. You can't wait until a heart attack happens, by then it's too late." So Norma and many other women are grabbing life by the reins and doing what they can to prevent heart disease through a good diet, physical activity, and talking to their doctor about risks and warning signs.

"I try to live a healthy lifestyle by eating healthy foods and finding creative ways to exercise—like dancing," says Norma, who has been touched personally by NIH's Heart Truth⁶³ public information campaign. The Heart Truth® message is paired with an arresting visual—the Red Dress®—designed to warn women that heart disease is their number one killer. Since 2002, the Red Dress® has been a powerful symbol to millions of women like Norma who share a common desire to protect their hearts.

Norma and thousands of other residents living in cities with populations at high risk for heart disease continue to benefit from annual Heart Truth Road Show events where they can learn about their personal risk for heart disease and receive educational materials to help them take control of their heart health. By March 2009, 69 percent of women were aware that heart disease is the leading cause of death among women, up from 34 percent in 2000.

⁶³ ®Heart Truth and Red Dress are registered trademarks of the U.S. Department of Health and Human Services (HHS)

Introduction

As the Nation's medical research agency, NIH is a trusted source of information for millions of Americans. Communicating useful health and science information to the American public—a cornerstone of the NIH mission—requires integrative strategies that appeal to NIH's many audiences. The public has many faces: patients, family members, health care providers, scientists, public health workers, voluntary health organizations, policy leaders, and industry. To communicate effectively, NIH uses a variety of strategies and tactics to reach audiences where they are and in culturally competent, accessible ways.

Good communication achieves many goals toward improving health:

- Increasing knowledge and awareness of a health issue, problem, or solution
- Influencing perceptions, beliefs, and attitudes that may change social norms
- Prompting action
- Demonstrating healthy behaviors
- Refuting myths and misconceptions

- Helping forge self-sustainable relationships with communities

Each NIH IC shares a similar set of challenges: translating complex science into useful information and identifying and selecting appropriate communication outlets for key audiences. IC communications teams work directly with intramural and extramural scientists in their mission areas to ensure that the materials they produce are based on the soundest science.

The NIH Office of the Director's Office of Communications and Public Liaison (OCPL) provides an umbrella of leadership and guidance and coordinates communication activities across NIH ICs so the agency provides clear, consistent, and informative materials to the American public. NIH employs a range of strategies to reach Americans, and in particular, the agency continually assesses the most effective and efficient ways to reach those most vulnerable.

Public Information Campaigns and Communications Clearinghouses coordinate the ideas and actions of public and private organizations to reach people where they are. [Clearinghouses](#) are resource centers that connect the public with answers to their questions and that work with NIH ICs to develop new resources according to public need. Each year, NIH distributes nearly 30 million science-based, health information publications to requestors who rely on NIH and its news stories, press releases, and publications for authoritative information. Information campaigns often package and deliver multiple communication products with the goal of either provoking a specific action or bringing about a behavioral change. NIH-sponsored health campaigns provide current, comprehensive, science-based information about the symptoms, diagnosis, and treatment of various diseases and conditions, often helping individuals to play a greater role in improving their health.

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Innovative Uses of Social Media that keep pace with modern technology enable NIH to connect with young and mobile audiences who rely nearly exclusively on electronic means of communication. Engaging and informative online resources—blogs, pod- and vodcasts, YouTube, wikis, and others—are powerful communication tools that NIH is using to reach crucial target audiences. NIH has created a presence with its portal for vodcasts and videos. [NIH Vodcast episodes](#) and the “NIH4Health” channel on YouTube reach millions of users each month.

Reliable, Authoritative, Accessible, Science-Based Health Information for a range of age groups is readily available online at the [NIH health information portal](#). All NIH ICs continuously contribute scientifically vetted materials to this site, including information in easy-to-read formats and in languages other than English.

Cooperative Interactions with the Media enable NIH to provide the press with access to scientific and health expertise and a vehicle to tell health and science stories. In turn, programs that teach media literacy help impressionable youth deconstruct media messages so they can identify a sponsor's motives. Companion strategies guide communicators in composing messages attuned to the intended audience's point of view.

Partnerships with Outside Organizations help NIH achieve its mission to share and translate the results of medical research. Partnering activities also may include seeking entertainment industry support for a health issue. NIH routinely and freely shares materials with public health organizations, advocacy groups, schools, and community health officials, and encourages the personalization of

health information based on individual and community needs.

Public Participation is a key part of NIH's ability to carry out its mission. NIH employs a multifaceted approach to public engagement and outreach. One approach is through the NIH Director's Council of Public Representatives (COPR)—a Federal Advisory Committee composed of up to 21 members of the public who provide the public's perspective into the NIH research priority-setting process as well as the agency's public health education and public engagement efforts. Through COPR, the agency connects directly with the public at the level of the NIH Director. The Council serves as the public's voice on issues relating to the NIH mission, informs the public of the research and health benefits gained through the public's investment in NIH, and helps NIH understand the public perspective and engage the public in NIH activities. Members of this group represent a wide variety of backgrounds based on geographic location, race, ethnicity, and experience, including patients, family members of patients, health care professionals, scientists, health and science communicators, and educators.

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NIH's "Clear Communication" effort builds upon sound research results provided by trans-NIH programs and activities. With this program, NIH aims to cultivate and contribute to a growing health literacy movement by increasing sharing of information including NIH educational products and research, lessons learned, and research in the area of health literacy. The program provides accessible materials and resources to help professionals reach individuals with literacy challenges, as well as guidelines on how to create such materials. Sections on the [Clear Communication website](#) are devoted to health literacy, plain language, cultural competence, and NIH-funded health literacy research.

On a larger scale, NIH health communication programs move people from awareness to behavior change and are aimed at the societal level. Efforts to reduce drunk driving, for example, have changed individual and societal attitudes, behaviors, and policies through multiple forms of intervention, including communication. Groups with defined structures, such as associations, clubs, or civic groups, are important vehicles for carrying health messages and for creating and sustaining policy changes at the local level.

NIH also works diligently to develop and deliver transparent and timely information about funding practices and policies to ensure that the engine of medical research discovery runs at top speed and that the scientific workforce's information needs are met. NIH communicates regularly with the scientific community, including grantees, industry, and the scientific and academic press, to give them the sources and tools they need to access the latest research results and information.

Catalogs of Health Communication and Information Campaigns & Clearinghouses Activities

In response to the mandate under SEC. 403 (a)(4)(C)(ii) of the of the Public Health Service Act to provide a catalog of information clearinghouses, included here is a live link to a website featuring [NIH's information clearinghouses](#). In response to the mandate under SEC. 403 (a)(4)(C)(iii) to provide a catalog of public education and information campaigns included here is a live link to a website featuring [NIH's Education and Awareness Campaigns](#).

Summary of NIH Activities

NIH ICs are congressionally mandated to provide science-based health information to the public. As

science and society change, the mode of information exchange needs to change, too. Near instant access to information through electronic media creates a new role for Federal agencies—trusted sources of credible information—to serve as a gateway for clear and balanced information about science and medicine, in a range of accessible formats.

New knowledge of human biology and advances in technology has given scientists the ability to better understand the language of human genes. This has thrust modern society into an age in which personalized medicine is nearing reality. That means that the results of modern scientific research are beginning to tell us how particular individuals will react to a medicine or a chemical in the environment, as well as which health problems they may be prone to. Having this individualized health information and understanding the role of cultural influences will enable Americans to implement prevention measures against a range of diseases and conditions.

A key aspect of the departure from "one-size-fits-most" medical care is individual involvement in health care and decision-making. Engaging the public in its own health is a crucial step toward achieving prevention-based medicine.

Delivering Health Information and Science News to the Public

Keeping the public informed about new developments in NIH-supported medical research is a primary goal of NIH health communication efforts. A variety of scientifically vetted, general health information and science news resources are available through NIH, including:

- [NIH Research Matters](#), an e-column offering a glimpse into research accomplishments of NIH and NIH-funded scientists using brief, accessible stories that describe research results and put them in perspective
- ["Research Results for the Public,"](#) a site that provides disease-by-disease descriptions of research progress and an interactive map of NIH research funding across the Nation
- ["NIH & Clinical Research,"](#) a health information site that features podcasts, vodcasts, and radio programs in English and Spanish on clinical research
- [NIH News in Health](#), a newsletter and online resource that provides practical and accessible health information monthly to public health workers, community centers, aging centers, voluntary health organizations, physicians, and hospitals
- ["Talking to Your Doctor,"](#) a site that offers NIH-produced resources from several ICs to enable patients to play an active role in their health care
- ["The Women's Health Resources Web Portal,"](#) a site created to promote awareness and facilitation of research on women's health by providing Web-based resources, including access to scientific literature and research reports, clinical trials opportunities, and consumer health information pertaining to women's health

Because the press is a major source of health information for the public, NIH staff members work every day to provide background for media sources and identify key knowledgeable scientists to help reporters develop their stories. OCPL is the central coordinator and responder for media relations at NIH. In addition, to help the press interpret medical information with greater ease and accuracy, NIH also offers a highly acclaimed, free annual training course, "Medicine in the Media," now in its eighth year.

NIH also has developed a network of public information officers (PIOs) at academic institutions nationwide to ease communication, encourage collaboration, and coordinate publicity between NIH PIOs and communications staff at NIH-funded grantee and contracted institutions.

In our Internet-driven society, the Web and related media are indispensable sources of news. Recent research has shown that a majority of Americans who request NIH information not only use it, but also

share it with others. More than 40 percent who use Web materials related to health take that information with them to their physicians' offices. The NIH homepage, developed and managed by OCPL's Online Information Branch, serves as entry point to the hundreds of individual NIH websites that comprise the NIH community of online programs, services, and information spanning thousands of health topics and research activities. One important page on the NIH website is "Get Involved at NIH" at <http://getinvolved.nih.gov/>, which serves as the NIH gateway for public participation, input, and feedback. Combined, the NIH websites, including those run by NLM, whose basic mission is to improve the dissemination of biomedical and health information, are accessed more than 3 billion times each year.

NIH and the Wikipedia Foundation are working together to make health and science information more accessible and reliable to the widest audiences possible.

In July 2009, NIH joined forces with the Wikimedia Foundation, the nonprofit, collaborative arm of Wikipedia®. Wikipedia is the international online encyclopedia that is the fourth largest Internet property. It attracts approximately 65 million visitors monthly and has information in 270 languages. NIH and Wikipedia are working together to make health and science information more accessible and reliable to the widest audiences possible. This historic "Academy" collaboration is the first of its kind for both organizations. NIH subject matter experts will contribute to Wikipedia and also help develop best practices for future sessions. [Guidelines](#) about how to contribute are available on the NIH website for scientists across the country. In addition, NIH communication offices have piloted use of social media for the past few years and will now implement newly released HHS [social media guidelines](#) to increase reach and to meet the audience where they are with added transparency and efficiency.

"[i on NIH](#)" is an Internet-based video program designed to educate and inform anyone interested in health-research news. For 30 minutes, once a month, i on NIH conveys the excitement of advances and important discoveries in medical research in a news-magazine style.

[NIH Radio](#) posts new stories each week to provide radio stations and the public with the latest information about NIH research findings, highlights of press conferences, and health campaigns. The NIH Radio News Service, now more than 20 years old, is available to millions of listeners on satellite radio through a feature called "NIH Health Matters," a 60-second spot aired on the HealthStar Radio Network and nearly 1,000 radio stations nationwide, including overnight airing on Washington, D.C.'s WTOP.

- "[NIH Research Radio](#)" is a biweekly podcast that can be listened to on a computer or downloaded into individual portable MP3 players.

To address the needs of those seeking more specific information about various diseases and conditions, NIH ICs produce a wide spectrum of more tailored science and health information in various formats, including the following selected examples:

- "[Healthy Moments](#)" is a radio series that provides tips to prevent and control diabetes, kidney disease, and related health disorders. The reports air on RadioOne's Majic 102.3 FM and two additional RadioOne, Inc. radio stations.
- The NIAMS Information Clearinghouse and the [NIH Osteoporosis and Related Bone Diseases National Resource Center](#)⁶⁴ produce and distribute health education materials in a variety of languages and formats on diseases and conditions of bones, joints, muscles, and skin to patients, health professionals, scientists, voluntary and professional organizations, and the media.
- NIH hosts online [Picture](#) and [Video](#) Galleries that showcase NIH-supported research results in vivid color and in motion. The images and videos illustrate various cutting-edge concepts in modern biomedicine and have been requested for use by *Discover* magazine and several textbook

publishers.

- An annual "[Medicine for the Public](#)" lecture series has been presented every fall since 1978. The series provides the public with information on medical research geared in a lay-friendly format. The lectures are free and span a wide range of topics such as cancer screening, mental health, asthma, and many others.
- Various NIH ICs take advantage of commemorative days—for example, National HIV/AIDS Awareness Day—to publicize the importance of pressing health issues. Announcements from top NIH leadership are picked up by the media and highlight dozens of health diseases and disorders that affect the American public, offering timely opportunities and suggestions for prevention and treatment.
- In FYs 2008 and 2009, NIH added nearly 1.4 million articles from the biomedical journal literature to [PubMed/MEDLINE](#), a vital tool for biomedical research, clinical medicine, and consumer health. The Indexing 2015 initiative is pursuing increases in the speed and efficiency of indexing through natural language processing and other automated techniques.

⁶⁴ The NIH National Resource Center is a partnership with support from NIA, the Eunice Kennedy Shriver NICHD, NIDCR, NIDDK, the NIH Office of Research on Women's Health, and the HHS Office on Women's Health.

Reaching Different Audiences

On January 21, 2009, President Obama issued a directive to all Federal agencies calling for greater transparency, public participation, and collaboration. In response to this directive, and in keeping with the work that has already been done by NIH to encourage public input and provide the public with science-based health information and knowledge about the science it conducts and supports, the agency posted a [Request for Information \(RFI\)](#) to offer a new public input opportunity. NIH received an unprecedented response from both individual organizations and members of the public and will work with the results to enhance health information. Information gathered will help NIH develop and disseminate health, medical, and scientific information to a wider variety of audiences.

The agency anticipates using new outreach strategies and tools, including community-level outlets and Internet-based social media, to connect with the diverse American public that includes patients, families, friends, scientists, health professionals, public health workers, industry, health care providers, congressional staff, and voluntary organizations.

As America continues to diversify, NIH continues to gather input from communities and groups on cultural factors. This information is essential for the development of high-quality, tailored health information. Individuals and communities require culturally appropriate information on specific health conditions or concerns, and NIH ICs work hard to develop quality products to meet this need. For example, NIH harbors a special responsibility to serve America's youth through targeted approaches that address the needs and wants of modern children and teens. Four examples of how NIH is meeting the information requirements of specific audiences are:

- The [NIH website](#) continues to incorporate new technologies, including customized streaming news feeds such as Really Simple Syndication (RSS), Podcasting and Vodcasting, and health video posted on NIH's Facebook page, YouTube, and Twitter sites, to reach the tech savvy segment of the population whose favored modes of communication are social media.
- [Control del dolor: Apoyo para las personas con cáncer](#) (*Pain Control: Support for People with Cancer*) are booklets produced in Spanish and English to address the needs of those suffering from cancer pain. They provide culturally sensitive information on cancer medicines and side effects,

communication, pain control methods, and coping methods for the physical and emotional effects of pain.

- Four sets of heart health booklets offer motivation and action steps to incorporate heart healthy behaviors into daily life for [Latino Americans](#) and [Filipino Americans](#). The booklets include references to culturally appropriate foods, activities, and situations.
- The NIH *MedlinePlus* magazine, and its bilingual Spanish counterpart *NIH Medline Plus Salud*, are quarterly consumer magazines focused on bringing the latest clinical findings to patients and their families. The magazines are complementary to the MedlinePlus and MedlinePlus en español websites, and are distributed to the public via doctors' offices nationwide.

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NIH also keeps tabs on the health information needs of population groups that need specialized information, and NIH ICs proactively develop tailored communications products and approaches. These include science-based fact sheets, checklist resources, public service announcements, K-12 educational materials, and more, such as:

- In 2007 the Trans-NIH American Indian and Alaska Native Health Communications & Information Work Group, with representation from 16 NIH ICs, began working with the Indian Health Service's National Community Health Representative Program on activities of mutual interest. To help increase awareness of the vast array of resources provided by the NIH, the Work Group sends quarterly mailings of health information to a network of 1,600 Tribal community health representatives nationwide who serve as lay health educators and patient liaisons in Native communities.
- Since 2006, NIH, in collaboration with the Coalition for Imaging and Bioengineering Research, has hosted several campus tours each year aimed at introducing congressional staffers and patient advocacy group members to the cutting-edge research programs and laboratory facilities of NIH.
- Fifteen NIH ICs collaborated to develop the 43 health topics included on the popular www.NIHSeniorHealth.gov website, which covers health topics of particular interest to older adults such as Alzheimer's disease, cataracts, shingles, exercise, nutrition, fall prevention, taking medicines, and Medicare basics—all in a clear, easy-to-read format.
- Because African Americans are at high risk for developing heritable kidney disease, NIH developed and promoted *The [Family Reunion Health Guide](#)* for use at African American family reunions. This resource has everything African American families need to talk about the connection between diabetes, high blood pressure, and kidney disease.

NIH also is engaged in sustained NIH media and multicultural outreach efforts. Staff members produce 4 radio programs, including Spanish language programming, that feature public service announcements, 60-second reports, and long-format interviews. NIH also produces the award-winning podcast series "Pinn Point on Women's Health." The series highlights topics in women's health research through conversations with NIH experts on a variety of subjects, and breaking news on women's health research in a segment titled "Hot Flashes."

Rapidly Responding to Time-Sensitive Issues

New challenges arise constantly in our fast-paced world. Often, health communications need to be developed swiftly to raise awareness or encourage people to take urgent and specific actions based on a new finding or a health threat. In developing its communications programs, NIH remains vigilant to the

need for timely communications materials. The following are selected examples from across NIH.

In 2009, a virus with clear pandemic potential, the 2009 H1N1 influenza virus, emerged. Because the scientific and public health communities had expected this scenario, NIH and HHS were poised to work collaboratively with other Federal agencies to prepare for a possible epidemic. In addition to a range of scientific and public health measures, NIH teamed with the U.S. Centers for Disease Control and Prevention (CDC) to provide consistent messaging in a coordinated and timely fashion for health consumers wanting the most up-to-date facts and guidelines about the 2009 H1N1 epidemic.

OCPL provides ongoing strategic and tactical advice on time-sensitive issues. The office works with NIH leadership, both in the OD and across NIH ICs, to ensure coherent, responsive messages. In 2009, OCPL was the focal point at NIH for communicating the impact of the [American Recovery and Reinvestment Act](#) (ARRA) by identifying and publicizing plans and funding opportunities. OCPL has been closely involved with the development of NIH processes for the agency's ARRA communication efforts.

Recognizing Problems and Taking Action

National data point to a serious crisis in that currently available health information is too difficult for average Americans to use to make health decisions.⁶⁵ The first ever National Assessment of Adult Literacy⁶⁶ determined that only 12 percent of U.S. adults had proficient health literacy, and more than a third of U.S. adults—77 million people—would have difficulty with common health tasks, such as following directions on a prescription drug label or adhering to a childhood immunization schedule using a standard chart.

The HHS [Healthy People 2010](#) initiative established improving health literacy as a national health objective. Following the April 2004 Institute of Medicine report, *Health Literacy: A Prescription to End Confusion*, NIH issued a series of program announcements to encourage empirical research on health literacy concepts, theory, and interventions as they relate to public health priorities identified in Healthy People 2010.

A growing research base⁶⁷ is investigating how advances in knowledge about health literacy can inform intervention strategies and have an impact on quality of life and on the reduction of health disparities in general and special populations. Various approaches to addressing this vexing problem currently are underway, such as:

- Determining the effect of low-income parents' literacy levels on safety information comprehension and adoption of behaviors to prevent child injury
- Testing a literacy-focused program that provides educational assistance from pharmacists at the time of hospital discharge to people hospitalized with heart problems
- Identifying the spectrum of medical errors and adverse drug events in the elderly and how literacy affects medication safety
- Evaluating the relationship between informed consent, health literacy, and the documents and tools used to communicate with those who might participate in research studies
- Testing the effectiveness of a clinic-based health literacy intervention to improve initial and repeat use of colorectal and breast cancer screening in rural areas

An important component of solving health-related problems is identifying and understanding the context in which gaps in knowledge and communication arise and persist. For example, many dentists do not feel sufficiently trained to provide services to people with special needs. To help increase access to dental care, NIH developed a [series of publications](#) to equip general dentists and dental hygienists with information they need to deliver quality oral care to people with developmental disabilities.

A 2006 survey completed by NIH and the American Association of Retired People (AARP) revealed that nearly two-thirds of adults older than age 50 use complementary and alternative medicine, but only one-third of them share that information with their physicians—creating the potential for serious complications. NIH launched a new patient/provider education initiative, "Time to Talk," which encourages open discussion of all health care practices to ensure safe and coordinated care.

Although the life expectancy of the American people has reached a historic high, along with it has come an increase in the number of people living with, and dying from, chronic debilitating diseases. By communicating to the public and the media the results of its important research in this area, NIH provides timely and helpful information to family members and loved ones of the dying.

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[Rethinking Drinking](#), a new website and downloadable booklet, aims to help many people reduce their risk for alcohol problems, a serious societal issue. The new materials present evidence-based information about risky drinking patterns, the alcohol content of drinks, the signs of an alcohol problem, along with information about medications and other resources to help people who choose to cut back or quit drinking.

As the American population ages, the Nation's disease burden is shifting toward conditions that affect older people. Building on the success of an earlier award-winning partnership with Home Box Office (HBO), in 2009, NIH and HBO copresented the multiplatform public health series, "[The Alzheimer's Project](#)," to help widen public understanding of this disease that affects millions of people and their caregivers.

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Many urgent health issues continue to remain "under the radar," unduly affecting vulnerable groups. For example, chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in the United States. NIH developed the [COPD: Learn More Breathe Better® Campaign](#), which encourages people at risk to get a simple breathing test and talk to their doctors about treatment options.

⁶⁵ For more information, see <http://www.health.gov/communication/literacy/issuebrief/>.

⁶⁶ For more information, see <http://nces.ed.gov/naal/>.

⁶⁷ For more information, see <http://www.nih.gov/icd/od/ocpl/resources/healthliteracyresearch.htm>.

Partnering With Outside Organizations

NIH ICs receive regular input from a wide range of outside organizations, and when appropriate, engage in strategic partnerships and collaborations that can enhance NIH's ability to carry out its mission as the Nation's medical research agency. Partners include nonprofit groups, such as voluntary health agencies and community-based organizations. These groups can increase the reach of NIH health communications and outreach programs. Agency interactions with such groups range from routine meetings to the establishment of novel programmatic initiatives and partnerships that can

include co-funding of research. These efforts are an important way for NIH to receive regular input from its public constituencies and to forward research announcements, research results, agency news, and scientific press releases.

Examples of projects involving NIH ICs and non-profit organizations include:

- [NCI's Community Networks Program](#), which is designed to reach communities and populations that [experience a disproportionate share of the cancer burden](#). These include African Americans, American Indians/Alaska Natives, Hawaiian Natives and other Pacific Islanders, Asians, Hispanics/Latinos, and underserved rural populations. Strategic partnerships and collaborations enhance vital training, research, and educational functions of this program.
- [NIMH's Outreach Partnership Program](#), which joins with national and state organizations to bridge the gap between research and clinical practice. The program helps disseminate the latest scientific findings; inform the public about mental disorders, alcoholism, and drug addiction; and reduce the stigma and discrimination associated with these illnesses. NIMH has established a formal process to ensure consistent, open dialogue with its major stakeholders through regularly scheduled meetings between their representatives and the NIMH Director and senior staff.
- [The NIAMS Health Partnership Program](#), a community-based, collaborative research program between NIAMS and Washington, D.C., area community organizations. Through research with underrepresented patients affected by arthritis and other rheumatic diseases, the program studies health disparities and their causes and provides direction for improving the health status and outcomes of affected minority communities. Its Community Health Center, located in the Columbia Heights area of northwest Washington, D.C., gives the community access to specialized care and health information, and provides NIH researchers with access to patients most affected by rheumatic diseases.
- [NIEHS's Partnership for Environmental Public Health](#), which brings together scientists, community members, educators, health care providers, public health officials, and policy makers. A hallmark of this program is that communities are actively engaged in all stages of the research, dissemination, and evaluation. This ensures that vital information about linkages between exposures and disease can be discovered and used to promote health and reduce the risk of disease across the populations at highest risk.
- [The NIDCR-hosted annual Patient Advocates Forum](#), which brings together voluntary health organizations with a shared interest in the oral health effects of their respective disorders and conditions. Begun in 2000, the forum provides an opportunity for NIH to solicit input from the public on a range of NIDCR activities and policies, and to keep the advocacy groups informed about ongoing and planned research programs of particular interest to their constituencies.

Where appropriate, NIH ICs partner with the private sector to reach target audiences and achieve agency health communication goals. Examples of projects involving NIH ICs and the private sector include:

- [The NEI Health Education Program Partnership](#), which consists of more than 70 public and private national organizations interested in eye health education. The purpose of the partnership is to establish ongoing, interactive, mutually beneficial relationships with the NEI and other organizations to facilitate collaboration; to exchange information, views, and materials on eye health education; and to identify and target audiences at higher risk of eye diseases and conditions.
- [The Bethesda Hospitals' Emergency Preparedness Partnership](#), a unique team of emergency responders from Federal, military, and private health care agencies. This partnership joins the NLM with three hospitals in close proximity—the NIH CC, the National Naval Medical Center, and Suburban Hospital—to integrate and leverage resources for local, regional, or national emergencies. Among the group's activities are periodic disaster drills.
- [The National Diabetes Education Program](#), which is co-led by the NIDDK and CDC, works with more than 200 partners at the Federal, State, and local levels to improve the treatment and outcomes for people with diabetes, promote early diagnosis, and prevent or delay the onset of type

2 diabetes. Partners include professional associations, national service and civic organizations, and community groups.

Outreach to the Scientific and Research Communities

In addition to communicating science and health news and information to the public, NIH reaches out to the scientific and research communities to share information and obtain input. Many of these communications campaigns are essential elements in the development of science policies that fit the needs of the NIH audiences that extend beyond researchers to include patients and advocacy groups that are vital participants in the research enterprise. For example, through one recent outreach effort, NIH obtained critical input that informed the agency's issuance of the [NIH Stem Cell Guidelines](#) in July 2009.

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In other outreach activities, NIH developed and disseminated timely information about several pressing issues relevant to the scientific community, such as [enhancements to the peer review process](#) and new opportunities and requirements resulting from implementation of [ARRA](#).

NIH continues to partner with the [ResearchChannel](#) consortium, a public service organization that broadcasts the latest research information free-of-charge, 24 hours per day through satellite and cable television systems—providing access to more than 30 million U.S. subscribers. Much like C-Span communicates political developments to a broad public audience, the ResearchChannel provides wall-to-wall coverage through DIRECTV of nothing but research. The channel also is available on 70 university and school-based cable systems in the United States and overseas.

NIH leads by example in addressing scientific workforce-related issues, and communication about these problems is a key element toward finding tractable solutions. In December 2008, NIH hosted the largest national conference ever on health disparities—the first summit of its kind that involved all NIH ICs and brought together more than 4,000 national and international clinicians, researchers, policy leaders, academicians, and community leaders. The conference spurred new lines of communication among researchers, spanning a broad range of fields and strategies related to combating health disparities and addressing the companion problem of low health literacy.

Following the release of the National Academies report, [Beyond Bias and Barriers: Fulfilling the Potential of Women in Academic Science and Engineering](#), NIH created a Working Group on Women in Biomedical Careers. Co-chaired by the NIH Director and ORWH Director, the group is currently working to address recommendations from two conferences held on the topic: "[The National Leadership Workshop on Mentoring Women in Biomedical Careers](#)," and "[Women in Biomedical Research: Best Practices for Sustaining Career Success](#)." NIH continues to spread the word about the meeting proceedings and their impact on the broader scientific community.

As a world health leader, NIH also must extend its reach to the international scientific community. NIH develops new partnerships among U.S. scientists, institutions, and counterparts abroad to advance research and training in the biomedical and behavioral sciences. The partnering activities foster communications about health and research needs and thus identify opportunities for collaboration with foreign science-funding agencies, the U.S. Department of State, U.S. technical agencies, and international organizations.

Several ICs have developed focused communications tools to provide assistance to, and enable bidirectional communication with, the scientific community and grantees in particular, such as:

- In 2009, NIGMS changed its [Feedback Loop](#) electronic newsletter, which had been published 3 times a year since 2005, into a blog that posts news and other information as it happens. Site users can submit comments and ask questions, which Institute staff answer. This interactive approach has been especially helpful in communicating time-sensitive information about ARRA.
- The "[NCRR e-Reporter](#)" fosters communication, collaboration and resource sharing in areas of current interest to scientists and the public. More than 2,400 subscribers include NCRR grantees, as well as other stakeholders in research, such as leaders in academia, industry, voluntary health organizations, patient advocacy groups, scientific professional societies, policy makers, and science teachers.
- The "[NEI Pipeline](#)" is an e-mail broadcast service intended to keep the vision research community informed of grant opportunities, new initiatives, and other newsworthy information concerning NEI and NIH.
- "[NIH Grant Cycle: Application to Renewal](#)," produced by NIAID, is an online tutorial that combines graphics and text to explain how to successfully compete for an NIH grant. A reinvention of NIAID's "[All About Grants](#)" tutorials, the new resource divides the funding lifecycle into 12 phases and offers stage-specific information and advice for scientific investigators.
- OCPL developed a constituency database, which contains approximately 400 contacts for advocacy organizations, colleges and universities, hospitals and research centers, and professional societies. Approximately 10 to 12 emails are distributed to this list annually, on topics such as the [NIH Peer Review Enhancement Effort](#); the [Research, Condition, and Disease Categorization system](#); [Public Access Policy](#); and relevant scientific meetings.

Conclusion

In this exciting and quickly evolving era of modern science, NIH has the responsibility—and the privilege—of finding novel ways to connect with the American public. This challenge goes beyond unidirectional delivery of health-related materials, since education involves much more than understanding information. Rather, this urgent task invites a dialogue with the general public, scientists, health care providers, and policy makers to assess what people know, what they want to know, and how to meet those needs of varied audiences. Bringing science to life through innovative materials and programs is a proud tradition of NIH. Thus, NIH continues to employ a wide variety of communication vehicles and makes information available through cutting-edge and audience-tested outlets and strategies.

Clear, yet savvy, health communication approaches are paramount to helping people take advantage of research advances to improve their health.

Notable Examples of NIH Activity

Key

E = Supported through **E**xtramural research

I = Supported through **I**ntramural research

O = **O**ther (e.g., policy, planning, or communication)

COE = Supported via congressionally mandated **C**enter of **E**xcellence program

GPRA Goal = **G**overnment **P**erformance and **R**esults **A**ct

ARRA = **A**merican **R**ecovery and **R**einvestment **A**ct

IC acronyms in **bold** face indicate lead IC(s).

Delivering Health Information and Science News to the Public

Disseminating Evidence-Based Health Information on Diabetes and Digestive and Kidney Diseases:

The National Diabetes Education Program (NDEP) and the National Kidney Disease Education Program (NKDEP) were created to disseminate evidence-based educational materials on diabetes and kidney disease, respectively. For example, the NDEP encourages people to take "small steps" to prevent type 2 diabetes. The NDEP also promotes the importance of comprehensive diabetes control in its Control Your Diabetes. For Life educational campaign. The NKDEP encourages African American families to discuss kidney disease at family reunions, and also provides tools and resources for health care providers to help coordinate care and improve patient outcomes for kidney disease. Both programs tailor materials for minority groups at high risk. Information Clearinghouses also provide key health information for patients, health care professionals, and the general public. A recent campaign highlighted the importance of using accurate methods to test hemoglobin A1c in people with diabetes who have sickle cell trait or other inherited hemoglobin variants. Other recent campaigns raised awareness of celiac disease and interstitial cystitis. The Weight-Control Information Network provides up-to-date, science-based information on weight control, obesity, physical activity, and related nutritional issues.

- For more information, see <http://www2.niddk.nih.gov/HealthEducation/>
- For more information, see <http://ndep.nih.gov/>
- For more information, see <http://nkdep.nih.gov/>
- For more information, see <http://win.niddk.nih.gov/>
- This example also appears in Chapter 2: *Minority Health and Health Disparities* and Chapter 3: *Clinical and Translational Research*
- (E) (**NIDDK**, CDC)

New Publications on Mental Health Disorders: NIH has developed several new mental health publications, including booklets and fact sheets on attention deficit hyperactivity disorder, panic disorder, obsessive compulsive disorder, bipolar disorder, bipolar disorder in children and teens, post-traumatic stress disorder, anxiety disorders, mental health medications, and a participants' guide to mental health research. Several of the publications also are available in Spanish and easy-to-read versions.

- For more information, see <http://www.nimh.nih.gov/health/publications/index.shtml>
- (O) (**NIMH**)

NIDCD Information Clearinghouse: NIDCD's Information Clearinghouse disseminates free health information in the areas of hearing, balance, smell, taste, voice, speech, and language to inquiring members of the public. For the years 2008-2009, the NIDCD Information Clearinghouse has maintained a toll-free phone and TTY number for the public and has ensured that NIDCD publications remain current and timely by adding or updating bilingual fact sheets and other educational materials for dissemination to the public. On average, the clearinghouse distributes 250,000 materials each year. In addition, the clearinghouse disseminates NIDCD health information materials at more than 28 professional conferences and health fairs around the country. Clearinghouse staff also have assisted in the planning and implementation of NIDCD's new campaign against noise-induced hearing loss, It's a Noisy Planet. Protect Their Hearing.

- For more information, see <http://www.nidcd.nih.gov/health/>
- (O) (NIDCD)

The Genetic and Rare Diseases Information Center (GARD): Since 1989, repeated studies and panels found that patients and families, as well as physicians, had great difficulties obtaining needed information about the almost 7,000 rare diseases known today. Then NIH established GARD. Since its inception more than 7 years ago, the information center has provided approximately 24,102 individualized responses about 6,497 different rare and/or genetic diseases. On January 30, 2008, GARD introduced new online information resources about rare and/or genetic diseases on the ORDR website for the public. Now, when a person submits a question to GARD about a particular condition, the question is edited and de-identified to ensure confidentiality and posted with its answer to the disease webpage on the ORDR website. A list of resources also is added to each disease webpage for additional information. Information specialists remain available to assist users directly and answer questions in both English and Spanish by telephone, e-mail, mail, or TTY. In the first year, visits to the webpages quadrupled from an average of 500 visits to 2,000 visits per month and continue to increase steadily. Given that the number of visitors and visits to the webpages continues to increase, with more than 250,000 additional individuals using the services of the information center, the sustained lower direct inquiry volume suggests that people are finding answers to their questions on the new Web disease pages without requiring the personal assistance of information specialists.

- For more information, see <http://rarediseases.info.nih.gov/GARD/>
- For more information, see <http://rarediseases.info.nih.gov/>
- (O) (ODP/ORDR, NHGRI)

Genetics Home Reference (GHR) and GeneTests: GHR is an online resource created for the general public that provides basic information about genetic conditions and the genes and chromosomes related to those conditions. In FYs 2008 and 2009, the system was expanded to include information on 200 more genetic conditions and 200 more genes. The website now covers more than 400 genetic conditions, more than 600 genes, all the human chromosomes, and information about disorders caused by mutations in mitochondrial DNA. GHR also links to GeneTests, a resource developed for health care professionals that provides current, authoritative information on genetic testing and is used in diagnosis, management, and genetic counseling. In addition to peer-reviewed disease descriptions, GeneTests includes voluntary listings of laboratories offering in-house testing and clinics providing genetic evaluation and genetic counseling. GeneTests is designed to promote the appropriate use of genetic services in patient care and personal decision making.

- For more information, see <http://ghr.nlm.nih.gov>
- For more information, see <http://www.ncbi.nlm.nih.gov/sites/genetests>
- (I) (NLM, NHGRI)

Exhibitions for the Public: NIH continues to present lively and informative exhibitions that enhance the awareness and appreciation of science, medicine, and history. *Visible Proofs: Forensic Views of the Body* closed in February 2008 after a highly successful 2-year run. A new exhibition, *Against the Odds: Making a Difference in Global Health*, which looks at the revolution in global health that is taking place in towns and cities around the world, opened in FY 2008 and will continue through FY 2010. An exhibit titled *Harry Potter's World: Renaissance Science, Magic, and Medicine* also opened in 2008. Using historical materials from the NIH, this exhibition explores Harry Potter's world and its roots in Renaissance magic, science, and medicine. Scores of school groups and other organizations visit the

exhibitions each year, and many more are able to access the accompanying online versions. Through a Traveling Exhibitions program, traveling versions of the exhibits also are made available to libraries across the Nation after they close at NIH, with six exhibits currently included in this program.

- For more information, see <http://www.nlm.nih.gov/hmd/about/exhibition/>
- (I) (NLM)

Linking Research Advances to NIH Funding: NIGMS publishes a monthly electronic newsletter, *Biomedical Beat*, that highlights recent research advances made by grantees and features cool scientific images. Through this and other activities, the Institute works to make connections between NIH grant funding and research advances by scientists at universities, medical schools, and other institutions.

- For more information, see <http://publications.nigms.nih.gov/biobeat>
- (O) (NIGMS)

MedlinePlus and MedlinePlus En Espanol: MedlinePlus and the Spanish language MedlinePlus En Espanol provide access to high-quality consumer health information on more than 800 diseases and conditions, with authoritative information from NIH, other government agencies, and health-related organizations. Enhancements in FYs 2008-2009 included improved search capabilities and addition of summary information. Content also was expanded to include information in more than 40 languages, addressing the growing needs of non-English-speaking patients. Go Local links from MedlinePlus, developed in partnership with libraries across the country, enable users to find relevant health services in local geographic areas. The number of Go Local sites increased to 34 in FY 2009, covering 46 percent of the U.S. population. The *NIH MedlinePlus Magazine* transmits the latest useful research findings in lay language, with feature stories on topics such as colorectal cancer, post-traumatic stress disorder, and childhood diseases. More than 600,000 copies of the magazine were distributed free to physician offices in FY 2009, up from 50,000 in FY 2006. In addition, a Spanish language edition, *Salud!*, was launched in FY 2009, as were online versions of both English and Spanish language magazines.

- For more information, see <http://www.medlineplus.gov>
- For more information, see <http://medlineplus.gov/spanish>
- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (I) (NLM)

Reaching Different Audiences

Education and Outreach: NCI's Office of Communications and Education (OCE) provides comprehensive cancer information to those at risk and to patients, caregivers, and health care providers. This information ranges from prevention, through treatment, to end-of-life topics. For example, clinical sites across the country extensively use NIH print- and Web-based materials to support their educational programs. OCE also provides public affairs, publications, audiovisual exhibits, and Web development support to NCI Divisions, Offices, and Centers. The Cancer Information Service (CIS) effectively communicates information through a Partnership Program to help reach those with limited access to health information; an Information Service that provides cancer information by telephone, TTY, instant messaging, and e-mail; and a Research Program that helps advance health

communication practices.

- For more information, see <http://www.cancer.gov/aboutnci/oce/>
- For more information, see <http://cis.nci.nih.gov/>
- For more information, see <http://cancer.gov/publications>
- For more information, see <http://www.cancer.gov/cancertopics>
- For more information, see <http://www.cancer.gov/espanol>
- This example also appears in Chapter 2: *Cancer*
- (E) (NCI)

Exercise Guide for Older Americans: In January 2009, NIH offered an update of its popular exercise guide, newly titled *Exercise and Physical Activity: Your Everyday Guide from the National Institute on Aging*. The guide is the result of a 2-year process overseen by the Task Force on Exercise and Physical Activity, which included top scientists conducting research on exercise and physical activity in older adults, as well as representatives from key organizations involved in promoting exercise and physical activity to the public, including CDC, the American College of Sports Medicine, and the International Council on Active Aging. Based on an intensive review by these experts of the evidence on physical activity, the updated publication reviews in lively, easy-to-understand language the benefits of physical activity for older people, discusses the importance of regular effort and goal setting, provides specific activities and exercises appropriate for varying strength and skill levels, and includes worksheets to help the reader track his or her progress. The new guide is proving popular already with the public; between 2000 and 2008, NIH distributed 1.2 million copies while in 2009, NIH has distributed more than 300,000 copies of the guide. NIH is undertaking an outreach effort on exercise, with the guide as a foundation, to encourage older people to become more physically active.

- For more information, see <http://www.nia.nih.gov/Exercise>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*
- (O) (NIA)

Health Information for Older Adults: NIH maintains a comprehensive program of health information aimed at older Americans. The NIA Information Center maintains a website and toll-free telephone lines to provide information in English and Spanish aimed at maintaining and improving health. Age Page fact sheets offer comprehensive, easy-to-read information on nearly 50 topics. The research update Spotlight on Aging Research (SOAR) provides current information on health and NIA activities to the public, policymakers, and researchers. The NIHSeniorHealth website enables the growing number of "wired seniors" to find credible aging-related health information in an online format that is compatible with their cognitive and visual needs, as determined by NIH-supported research; it includes 42 health topics developed by 12 NIH Institutes and one topic contributed by the Centers for Medicaid and Medicare. NIH also has developed a senior-friendly curriculum for people who train older adults to use computers. The Alzheimer's Disease Education and Referral (ADEAR) Center is the Federal government's primary source of information for patients, caregivers, health providers, policymakers, and the general public on Alzheimer's disease- and age-related cognitive change. The Center maintains a national database of clinical trials and develops easy-to-read materials in English and Spanish. In 2009, NIH collaborated with HBO Documentary Films, in association with the Alzheimer's Association, Fidelity Charitable Gift Fund, and Geoffrey Beene Gives Back Alzheimer's Initiative, on The Alzheimer's Project, which featured four documentary films, 33 supplemental films, a website, and a community-based information and outreach effort, with a companion book.

- For more information, see <http://www.nia.nih.gov/Alzheimers>

- For more information, see <http://www.nia.nih.gov/HealthInformation/Publications>
- For more information, see <http://www.NIHSeniorHealth.gov>
- (E) (NIA, NLM)

Know Stroke Efforts and New Stroke Slogan: In 2004, NIH entered a partnership with CDC to launch a grassroots education program called Know Stroke in the Community. The program was designed to identify and enlist the aid of community leaders who work as "Stroke Champions" to educate their communities about the signs and symptoms of stroke and the need for immediate action. The program focuses on reaching African Americans, Hispanics, and seniors in communities that have the health care systems in place to treat stroke. To date, the program has been implemented in 12 cities, educating 184 Stroke Champions who have conducted more than 600 community events. The program was expanded this year to Charleston, South Carolina, and, as a follow-up to that program, materials will be developed for coastal communities with unique dialects. NIH also recently expanded its public education programs by collaborating with the Brain Attack Coalition (BAC) to develop a new action-oriented message that all member organizations could use with their current stroke awareness efforts. The BAC is a group of organizations committed to stroke prevention and treatment chaired by NINDS. The new slogan—"Stroke strikes fast. You should too. Call 9-1-1."—was launched in May 2009 during Stroke Awareness Month.

- For more information, see <http://stroke.nih.gov/about/>
- This example also appears in Chapter 2: *Neuroscience and Disorders of the Nervous System* and Chapter 2: *Minority Health and Health Disparities*
- (O) (NINDS)

Medicine in the Media Course: NIH presents a free annual training opportunity to help journalists evaluate and report on medical research. The program was created to address a growing need to improve the reporting of scientific and medical research findings by the media. Now in its eighth year, the course examines the challenges and opportunities inherent in the process of communicating the results of medical research to the public. The interactive program lays out the critical basics of differentiating strong from weak scientific information, well-designed vs. poorly-designed scientific studies, and "strength of opinion vs. strength of evidence." Stressing an evidence-based approach and re-examining intuitive beliefs about medicine, the course prepares participants for the crucial task of interpreting and evaluating research findings, including methods to select stories with meaningful messages for the public and place them in the appropriate context. Sessions are interactive, with hands-on opportunities to apply lessons learned, and incorporate journalists' unique perspectives on the public's need for useful medical knowledge. The program is highly competitive and attracts media and journalism professionals from around the country for a 3-day intensive workshop. Feedback from participants indicates that the program changed their fundamental understanding of what is worthy of reporting and helped them to provide appropriate context regarding the strengths, weaknesses, and relevance of a given study's findings. Participants frequently recommend the program to colleagues.

- For more information, see <http://medmediacourse.nih.gov/>
- For more information, see http://medmediacourse.nih.gov/02_agenda.html
- (E) (ODP/OMAR)

National Child and Maternal Health Education Program (NCMHEP): To develop a national maternal and child health education program with input from stakeholders, NIH created a program to effectively review and translate maternal and child health research findings into new knowledge that

can be disseminated to clinicians and their patients. Forums have been created in which major stakeholders in maternal and child health can work together to review scientific findings and decide how to best communicate their findings to targeted audiences. NIH has identified four areas on which the NCMHEP will focus: prematurity and low birth weight, pediatric obesity, infant mortality, and environmental influences on child health and development.

- (O) (NICHD)

SIDS Outreach in Minority Communities: Since 1994, when NIH launched its campaign to reduce the risks of Sudden Infant Death Syndrome (SIDS), overall SIDS rates have declined significantly, yet the disparities continue to exist. Today, babies in the American Indian and Alaska Native communities are twice as likely to die from SIDS as white infants. To help eliminate this disparity, NIH, in collaboration with Native American Management Services, Inc., developed adaptable, culturally appropriate SIDS risk-reduction materials for use in five Indian Health Service Areas—Northern Tier-Aberdeen, Billings, Bemidji, Portland, and Alaska. Under the guidance of a community-based work group, educational materials have been developed based on recommendations from the five areas. The outreach project is called "Healthy Native Babies: Honoring the Past, Learning for the Future." Project materials include a training manual and a CD-ROM. The interactive CD-ROM that has been developed includes templates for a variety of SIDS risk-reduction educational materials. It contains photographs of American Indian and Alaska Native families and infants from the five regions, taken by local photographers. These photographs can be incorporated into educational materials such as posters, flyers, brochures, and postcards.

- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (O) (NICHD)

Science Education Partnership Award (SEPA) Program: SEPA increases the public's understanding of medical research by: 1) increasing the pipeline of future scientists and clinicians, especially from underserved and rural kindergarten to grade 12 (K-12) students, and 2) engaging and educating the general public on health-related advances made possible by NIH-funded research. By creating relationships among educators, museum curators, and medical researchers, SEPA encourages the development of hands-on, inquiry-based curricula that inform subjects about timely issues, including obesity, diabetes, stem cells, and emerging infectious diseases. Additionally, SEPA projects are designed to enhance public trust by focusing on topics such as the clinical trials process, patient safeguards, and medical research ethics. Through SEPA exhibits at science centers and museums, the program provides educational and community outreach activities to tens of thousands of people every year. In FY 2008, SEPA supported 68 projects, of which 50 targeted middle- and high-school students and 18 were based in science centers and museums.

- For more information, see <http://www.ncrr.nih.gov>
- For more information, see <http://www.ncrrsepa.org>
- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (E) (NCRR)

National Network of Libraries of Medicine (NN/LM): With more than 5,800 full and affiliate members representing academic health sciences libraries, hospital libraries, public libraries, and community-based organizations, the NN/LM plays a pivotal role in NIH's outreach programs to reduce health disparities and improve health information literacy. In FYs 2008-2009, NIH funded more than 400

community-based projects to enhance access to health information for health disparity and other medically underserved populations, building upon longstanding relationships with institutions providing health-related services and information to health disparity populations and developing many new relationships with schools, churches, public health departments, and others interested in improving health literacy and information access. Projects took place in rural and inner city communities and special populations in 35 states and the District of Columbia. The NN/LM also is a key player in the MedlinePlus "Go Local" service, which provides information about local community services to complement the nationally applicable health information in MedlinePlus. Go Local coverage reached 46 percent of the U.S. population in FYs 2008-2009. With an excellent track record of providing access to health information for clinicians and patients displaced by disasters, the NN/LM is the backbone of NIH's strategy to promote more effective use of libraries and librarians in local, State, and national disaster preparedness and response efforts. In FY 2008, a major initiative was the development of a national NN/LM Emergency Preparedness Plan to ensure backup health library services in the aftermath of a disaster and establish librarians as key community resources in disaster planning and response.

- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (E) (NLM)

Minority Health Information Access: An NIH outreach goal is to reduce health disparities among African American, Hispanic, and Native American populations by using a variety of approaches to promote access to and use of health information among diverse communities. The Historically Black Colleges and Universities (HBCU) ACCESS Project, developed in partnership with the United Negro College Fund Special Programs, provides technical assistance, training, and funding for locally developed projects incorporating the use of NIH information resources in HBCU campuses and communities. The Environmental Health Information Partnership enhances the capacity of 20 academic institutions that provide health-related services and information to health disparity populations by supporting their efforts to reduce health disparities through the access and use of environmental health information. Projects to increase the knowledge of Native Hawaiian community members about health information were completed at the community of Miloli'i and Waimanolo Health Center. At Cankdeska Cinkana Tribal College, Spirit Lake Nation, a health-related education program was developed along with tribal library improvements. Specialized websites, developed and expanded in partnership with community representatives, collect and organize information for specific populations such as Asian Americans, American Indians, and peoples of the Arctic. In the Lower Rio Grande Valley, the VIVA! Peer Tutors program at a magnet health high school is an award-winning effort to involve high school students in teaching their peers about online health information. The project has been extended to other schools and expanded to include promotion of health careers.

- For more information, see <http://sis.nlm.nih.gov/outreach.html>
- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (I) (NLM)

Rapidly Responding to Time-Sensitive Issues

Guidelines for the Medical Management of HIV: HHS issues Federal guidelines for the medical management of HIV infection and its associated co-infections, including antiretroviral treatment of HIV disease, prevention and treatment of opportunistic infections, and prevention of mother-to-child

transmission of HIV. The guidelines are written, reviewed, and updated by working groups of the NIH OAR Advisory Council made up of HIV experts from across the country, including physicians, pharmacists, researchers, and community representatives. The guidelines represent the state of knowledge regarding the medical management of HIV disease in the United States. As the introduction and/or availability of new therapeutic agents, new clinical data, and emerging disease threats may change therapeutic options and preferences rapidly, the guidelines are updated frequently and are available as a "living document" on the *AIDSinfo* website. Updates that recently were added to the *AIDSinfo* website include the *FDA Alert: Use of Antivirals Tamiflu and Relenza in Children* and the *CDC Interim Guidance-HIV-Infected Adults and Adolescents: Considerations for Clinicians Regarding Novel Influenza A (H1N1) Virus*.

- This example also appears in Chapter 2: *Infectious Diseases and Biodefense*
- (O) (OAR)

Recognizing Problems and Taking Action

It's a Noisy Planet. Protect Their Hearing: Approximately 26 million American adults are estimated to have high-frequency hearing loss caused by exposure to noise at work or during leisure activities. Since 1999, NIH has collaborated with the National Institute for Occupational Safety and Health on WISE EARS!®, a national education campaign to increase awareness about noise-induced hearing loss among the public and workers. In October 2008, NIH expanded these efforts by launching It's a Noisy Planet. Protect Their Hearing. This new campaign is designed to increase awareness among parents of children ages 8 to 12—or tweens—about the causes and prevention of noise-induced hearing loss. With this information, parents and other adults can encourage children to adopt healthy habits that will help them protect their hearing for life.

- For more information, see <http://www.noisyplanet.nidcd.nih.gov>
- (O) (NIDCD)

Providing Science-Based Oral Health Information: NIH provides science-based oral health information tailored to meet specific needs. Two examples are described here.

- *Practical Oral Care for People with Developmental Disabilities:* Finding dental care in the community is challenging for people with developmental disabilities. Many dentists do not feel trained sufficiently to provide services to people with special needs. To help increase access to dental care, NIH developed a series of publications to equip general dentists with information they need to deliver quality oral care to persons with developmental disabilities. The series includes continuing education (CE) programs for dentists and dental hygienists and a guide for caregivers describing their important role in maintaining good oral health for their family member or client. The modules are so popular that NIH has extended the CE credit through 2011.
- *Spanish-Language Oral Health Website:* The Special Care Dentistry Association partners with NIH in this important health education outreach—Spanish-Language Oral Health Website. This new Spanish-language website tailored for U.S. Hispanics/Latinos increases Spanish speakers' access to science-based oral health information. The site recently was tested in two cities; participants were Spanish-dominant and bilingual Latinos with backgrounds from different countries of origin and with varying levels of education. The test was to ensure the new website is understandable, credible, and attractive to the intended audience. Other goals included understanding the approach Latinos take when seeking health information online, what they think of the quality of online health information, and whether there are significant differences between Spanish-dominant and bilingual

individuals.

- For more information, see <http://www.nidcr.nih.gov/OralHealth/Topics/DevelopmentalDisabilities/>
- For more information, see <http://www.nidcr.nih.gov/espanol>
- This example also appears in Chapter 2: *Life Stages, Human Development, and Rehabilitation* and Chapter 2: *Minority Health and Health Disparities*
- (O) (NIDCR, NICHD)

Reaching Out to Teens and Health Care Professionals: In the spring of 2009, NIDA unveiled NIDAMED, its first comprehensive physicians' outreach initiative. NIDAMED gives medical professionals a variety of information, including tools and resources, to help in screening patients for tobacco, alcohol, and illicit and nonmedical prescription drug use. The NIDAMED website contains links to numerous resources for health care professionals: an online screening tool titled NIDA-Modified Alcohol, Smoking, and Substance Involvement Screening Test (NM ASSIST); two guides for clinicians (quick reference and a comprehensive resource guide); a number of key NIDA publications, such as the *Principles of Drug Abuse Treatment: A Research-Based Guide*, *The Science of Addiction*, a *Commonly Abused Drugs Chart*, and a postcard that encourages patients to "Tell Your Doctor About All the Drugs You Use." The NIDAMED initiative stresses the importance of the patient-doctor relationship in identifying and intervening early in patients' drug use behaviors before they evolve into life-threatening conditions. NIH is planning to hold its third annual Drug Facts Chat Day in November 2009. These events let students and teachers in classrooms across the United States ask questions of the Nation's top experts in the field of drug abuse and addiction. NIH staff will gather in a computer lab on the event day and will respond to submitted questions in real time. Chat Day events have proven to be a resounding success. The inaugural event elicited more than 35,000 questions.

- For more information, see <http://www.nida.nih.gov/nidamed>
- For more information, see <http://www.nida.nih.gov/scienceofaddiction>
- For more information, see <http://www.drugabuse.gov/chat>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*
- (E) (NIDA)

Rethinking Drinking: To help people recognize and reduce their risk for alcohol problems, NIH recently launched an interactive website and supporting booklet, Rethinking Drinking. These new NIH resources offer evidence-based information about risky drinking patterns, the alcohol content of drinks, and the signs of an alcohol problem, along with information about medications and other resources to help people who choose to cut back or quit drinking. The website also provides tools, such as calculators that can be personalized by the user to estimate the alcohol content in common cocktails.

- For more information, see <http://rethinkingdrinking.niaaa.nih.gov>
- (E, O) (NIAAA)

Children and Clinical Studies: Medical research in children has saved lives and improved health and well-being, yet parents often are reluctant or uncertain about allowing their child to participate in a clinical study. The Children and Clinical Studies campaign helps parents and others to learn more about how clinical research is conducted in children, so that they can make well-informed decisions about whether to participate. Its website, which is available in English and Spanish, combines practical information with award-winning video footage of parents, health care providers, and children themselves discussing the rewards and challenges of participating in research. Educational materials

for parents and health care providers can be requested through the site, as well.

- For more information, see <http://www.nhlbi.nih.gov/childrenandclinicalstudies/index.php>
- This example also appears in Chapter 3: *Technology Development*
- (E) (NHLBI, NCRR, NICHD)

Partnering with Outside Organizations

Disaster Information Services: A Disaster Information Management Research Center was established in FY 2008 with the aim to facilitate access to disaster information, promote more effective use of libraries and disaster information specialists in disaster management efforts, and ensure uninterrupted access to critical health information resources when disasters occur. A disaster information website provides access to a broad range of emergency preparedness and response information. The Center also collaborates with the Navy National Medical Center, Suburban Hospital, Johns Hopkins Medicine, and NIH CC in the Bethesda Hospital Emergency Preparedness Partnership to provide backup communication systems and develop tools for patient tracking, information sharing and access, and responder training and to serve as a model for hospitals across the Nation. NIH also develops advanced information services and tools to assist emergency responders when disaster strikes. WISER (Wireless Information System for Emergency Responders) was developed for use during hazardous materials incidents and is available on the Internet or for downloading onto PDAs and PCs. Usage continues to grow, with more than 47,000 downloads onto PDAs in FY 2008. Radiation Event Medical Management (REMM) is a downloadable toolkit for use by health care providers during a mass casualty radiation event, with a version for mobile platforms released in FY 2008. Developed in collaboration with the HHS Office of Public Health Preparedness, REMM includes procedures for diagnosis and management of radiation contamination and exposure, guidance for use of radiation medical countermeasures, among other features to facilitate medical responses to radiation emergencies.

- For more information, see <http://disasterinfo.nlm.nih.gov>
- For more information, see <http://wiser.nlm.nih.gov>
- For more information, see <http://remm.nlm.nih.gov>
- This example also appears in Chapter 3: *Disease Registries, Databases, and Biomedical Information Systems*
- (I) (NLM)

Partnerships for Environmental Public Health: NIH is developing a unified program referred to as "Partnerships for Environmental Public Health" (PEPH). PEPH will support activities to build new partnerships with community groups/stakeholders, develop and/or disseminate educational and outreach materials, enhance communication with partners (i.e., town meetings, forums on selected topics), evaluate (process and outcome evaluations) strategies to quantify public health impact, or engage community and researchers in Environmental Health Science research projects. The purpose of this program is to provide support for grantees already working in this area to enhance current grant activities within the scope of the peer-reviewed application and to encourage scientists with a traditional research focus to communicate/translate their research into materials or messages that are useful to other groups, such as the lay public, health care professionals, decisionmakers, or educators. Building partnerships and translating research to communities is an important component in promoting health and preventing exposures that may have adverse human health effects. By building environmental health and science literacy, community residents are better prepared and equipped to take personal

and community action to reduce exposures. Partnerships between researchers and community groups foster trust and lead to the identification of environmental health issues of concern to community residents, which may enhance the research results due to increased community participation.

- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (E) (NIEHS)

Outreach to the Scientific and Research Communities

AIDS Information Services: NIH manages the HHS-wide *AIDSinfo* service, which offers the latest federally approved information on HIV/AIDS clinical research, treatment and prevention, and medical practice guidelines that are developed by working groups under the auspices of the OAR Advisory Council. An *AIDSinfo* trans-agency steering group spans NIH, FDA, HRSA, and CDC. *InfoSIDA*, a Spanish-language version, features a customized home page and a search engine that locates Spanish-language resources within *AIDSinfo*. A new initiative to incorporate tens of thousands of abstracts from AIDS-related conferences held over the last decade into NIH's Web-based electronic information services also is underway, and testing for the first public release of the new data was conducted in FY 2009. In addition to providing information systems, NIH supports community outreach programs for underserved communities and special populations to promote improved access to HIV/AIDS information for health professionals, patients, the affected community, caregivers, and the general public. Emphasis is placed on supporting community-based organizations, libraries, faith-based organizations, and health departments to design and implement local programs that include information access topics related to information retrieval, skills development, Internet access, resource development, and document access, e.g., through collaboration with local public libraries. In FYs 2008-2009, NIH made 25 community outreach awards.

- For more information, see <http://aidsinfo.nih.gov>
- For more information, see <http://aidsinfo.nih.gov/infoSIDA/>
- For more information, see http://sis.nlm.nih.gov/outreach/hiv_outreach.html
- This example also appears in Chapter 2: *Minority Health and Health Disparities*
- (I) (NLM)

NIH Consensus Development Program: This program, administered by the Office of Medical Applications of Research (OMAR) within the Office of the Director, NIH, was established in 1977 as a mechanism to assess, translate, and disseminate the results of biomedical research. Since its inception, OMAR has conducted more than 120 Consensus Development Conferences, and 30 State-of-the-Science (formerly "Technology Assessment") Conferences. The program generates evidence-based statements addressing controversial issues in medicine and public health that are useful and relevant for health care providers, policymakers, patients, researchers, and the general public. The conferences are structured around key questions, including questions on the efficacy, risks, and clinical applications of a technology, along with current gaps in knowledge to help formulate directions for future research. For every conference, a systematic evidence review is performed through a partnership with the Agency for Healthcare Research and Quality to serve as the foundation upon which the conference will build. Experts in the field provide additional input and insights through several days of oral presentations. The conferences also contain sessions for public input and discussion. A multidisciplinary, nonadvocacy, independent panel free from scientific or financial conflicts considers all of this information, and then writes a statement answering the posed conference questions. Consensus and state-of-the-science statements are disseminated widely after the conference to either impact

clinical practice—when evidence strongly supports the use (or avoidance) of a particular intervention— or to direct future research—when important gaps in knowledge have been identified. Upcoming conferences in 2010 include: Enhancing Use and Quality of Colorectal Cancer Screening; Lactose Intolerance and Health; Vaginal Birth After Cesarean: New Insights; Preventing Alzheimer's Disease and Cognitive Decline; and Inhaled Nitric Oxide Therapy for Preterm Infants.

- For more information, see <http://consensus.nih.gov/>
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (ODP/OMAR)

Partners in Information Access for the Public Health Workforce (PH Partners): PH

Partners, a 12-member public-private collaboration initiated by NIH, the Centers for Disease Control and Prevention, and the National Network of Libraries of Medicine assists the public health workforce to make effective use of electronic information sources. The Partners website, PHPartners.org, provides unified access to public health information resources produced by all members of the Partnership, as well as other reputable organizations. One of the most popular resources on the site is the Healthy People 2010 Information Access Project. In FY 2008, the website was expanded with more than 650 new links, and two new topic pages covering nutrition and workforce development were added.

- For more information, see <http://www.PHPartners.org>
- (I) (NLM)