# The National Library of Medicine Toxicology Information Outreach Panel Report of the 12th Annual Meeting



Widening the Door to Access: HBCUs/MEIs and Tribal Colleges







Department of Health and Human Services National Institutes of Health National Library of Medicine

#### THE NATIONAL LIBRARY OF MEDICINE

### TOXICOLOGY INFORMATION OUTREACH PANEL

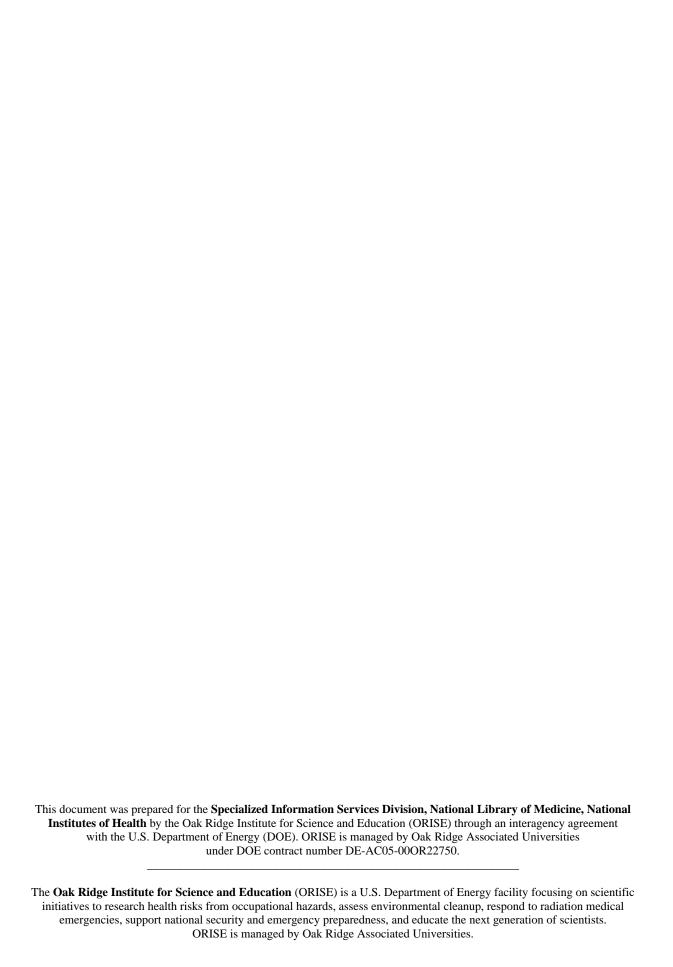
## A REPORT OF THE $12^{TH}$ ANNUAL MEETING

Widening the Door to Access: HBCUs/MEIs and Tribal Colleges

Bethesda, Maryland March 14, 2003

Prepared for Specialized Information Services Division National Library of Medicine

Prepared by
Medical Education and Outreach Group
Oak Ridge Institute for Science and Education



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Toxicology Information Outreach Panel: A Report of the 12 <sup>th</sup> Annual Meeting	

## CHAIRMAN: Dr. Bailus Walker, Jr., Howard University PROJECT DIRECTOR: Ms. Cynthia Gaines, National Library of Medicine PROJECT ADVISOR: Ms. Rose Foster, Oak Ridge Institute for Science and Education

Panel Members from Participating HBCUs/MEIs Dr. Ann Barbre, *Xavier University of Louisiana*Dr. Mohamed Bayorh, *Morehouse School of Medicine* 

Ms. Norma Bean (for Dr. Ted Bates), Texas Southern University

Ms. Kathy Block, Hampton University

Dr. Robert Copeland (for Dr. Robert Taylor), Howard University

Ms. Sarah Danner, Oglala Lakota College

Dr. Diogenes Herreno-Saenz, University of Puerto Rico Medical Sciences Campus

Dr. Henry Lewis, III, Florida A&M University

Dr. Joseph McQuirter, Charles R. Drew University of Medicine and Science

Dr. Alfred Nyanda, Meharry Medical College

**Panel Consultants** 

Dr. Melvin Spann, National Library of Medicine Consultant, TIOP Executive Secretary

Dr. Max Lum, National Institute for Occupational Safety and Health

National Library of Medicine

Ms. Cassandra Allen, Specialized Information Services Division

Ms. Gale Dutcher, Head, Office of Outreach and Special Populations, SIS

Ms. Cindy Love, Specialized Information Services Division

Ms. Martha Szczur, Deputy Associate Director, Specialized Information Services Division

Dr. Jack Snyder, Associate Director, Specialized Information Services Division

Distinguished Guests

**Participants** 

Dr. Donald A.B. Lindberg, Director, National Library of Medicine

Toxicology Information Outreach Panel: A Report of the 12 <sup>th</sup> Annual Meeting		



12th Annual Meeting of the
Toxicology Information Outreach Panel
March 14, 2003, 9:00 a.m.-4:30 p.m.
National Library of Medicine
6707 Democracy Plaza, Suite 510
SIS Conference Room
Bethesda, Maryland

#### **AGENDA**

9:00–9:15 a.m.	Opening Remarks	Bailus Walker, Ph.D. Chairman, TIOP
9:15–9:30 a.m.	Welcome & Introductions	Marti Szczur Deputy Associate Director, SIS
9:30–10:15 a.m.	Discussion of SIS Vision & Priorities	Jack Snyder, M.D. Associate Director Specialized Information Services
10:15–10:30 a.m.	BREAK	
10:30–12:00 noon	SIS Update	Marti Szczur & SIS Staff
12:00–1:00 p.m.	Demonstration of NLM Resources (Working Lunch)	SIS Staff
1:00–3:00 p.m.	Presentation of Draft for Environmental Strategic Plan	Melvin Spann, Ph.D. Henry Lewis, Ph.D. Florida A & M University
	Discussion	TIOP Members
3:00–3:30 p.m.	BREAK	
3:30–4:30 p.m.	Welcome to New Chairman Presentation of Certificates of Services and Photography	Donald A.B. Lindberg, M.D.  Director, NLM  Jack Snyder, M.D.  Cynthia Gaines, NLM
4:30 p.m.	<b>Meeting Summary</b>	Bailus Walker, Ph.D.

Toxicology Information Outreach Panel: A Report of the 12 <sup>th</sup> Annual Meeting	

## DEPARTMENT OF HEALTH AND HUMAN SERVICES NATIONAL INSTITUTES OF HEALTH

## NATIONAL LIBRARY OF MEDICINE DIVISION OF SPECIALIZED INFORMATION SERVICES

REPORT OF THE TWELFTH ANNUAL MEETING OF THE TOXICOLOGY INFORMATION OUTREACH PANEL MARCH 14, 2003

#### **OVERVIEW**

Martha Szczur, Deputy Associate Director, National Library of Medicine (NLM) Division of Specialized Information Services (SIS), called the meeting to order and stated three objectives to be accomplished:

- To highlight new activities at SIS and NLM and introduce the new SIS associate director.
- To introduce a draft strategic plan for an expanded role for the Panel, including a new name.
- To recognize each Panel member with a certificate of appreciation for his/her contribution to NLM as a Toxicology Information Outreach Panel (TIOP) member.

Ms. Szczur introduced Dr. Jack Snyder, new SIS Associate Director, whose appointment came after an extensive search for a renowned expert in the field of toxicology and environmental health. Dr. Snyder brings to SIS not only this expertise, but a diverse background. A physician/attorney with advanced degrees and experience in pharmacology, toxicology, pathology, public health, and occupational medicine, Dr. Snyder has taught at universities and also been a practicing physician. His alma maters include Northwestern University, Georgetown University, Johns Hopkins University, George Washington University, and the Medical College of Virginia. With his legal training and experience in practicing law, he brings an interest in and knowledge of environmental justice, which was one of the catalysts for forming the TIOP in 1991.

Dr. Snyder expressed his delight at his new association with the NLM, SIS, and this Panel. He gave his overall perspective of SIS's vision for the future, outlined the content of the environmental health information databases at NLM/SIS, discussed the methodologies employed in disseminating environmental health information, and discussed the current issues and challenges facing SIS. An interactive discussion followed.

Following a short break, Ms. Szczur gave a slide presentation on SIS activities and an online "tour" of the SIS Web site, highlighting the "Special Topics" pages of the site that professionals can use to get more indepth information and conducting sample searches in selected databases, including TOXNET, Haz-Map, ALTBIB, and Tox Town. The demonstrations sparked an interactive dialogue and exchange of ideas.

Cassandra Allen, Outreach Librarian, SIS, demonstrated changes in MEDLINE/PubMed and MEDLINEplus.

Dr. Melvin Spann, TIOP Executive Secretary, presented an outline for the development of a strategic plan for the Panel, which included a proposed restructuring of the Panel and a new name to more accurately reflect the new focus of the Panel's activities.

Gale Dutcher, Head, Office of Outreach and Special Populations, SIS, distributed a proposed mission statement, which was then discussed item by item.

Ms. Allen announced that Dr. Henry Lewis III, Dr. Robert Copeland, and Dr. Melvin Spann would be presenting a panel discussion on TIOP at the upcoming Medical Libraries Association Meeting (MLA), which will broaden awareness of TIOP in a public forum.

The Panel engaged in a final discussion on the future focus of its activities.

Following an afternoon break, Dr. Donald Lindberg, NLM Director, and Dr. Snyder presented certificates to each of the members present.

In honor of Dr. Walker's 10 years of service as TIOP Chairman, he was presented with a special gavel plaque and Dr. Lewis, as the new TIOP Chairman, was presented with a gavel that will be passed on to each successive chairman of the Panel.

Dr. Lindberg gave closing remarks and Dr. Walker noted Dr. Lindberg's support of the Panel over the years.

Please note that the order of events as reported here is not the same as in the original agenda. The order of presentation was altered because the chairman's arrival was delayed.

#### NLM/SIS VISION AND PRIORITIES

Dr. Jack Snyder discussed his vision for SIS's future. He envisions SIS developing a public domain portal for environmental and public health information. The aspect most relevant to this Panel is participation in the government's efforts to narrow the digital divide and to remedy disparities. He noted that each person's perception of disparity is different and all need to be addressed. NLM's contributions are distinguished by having an informational orientation in the collection and dissemination of information. He characterized the "consumers" of NLM's information as falling into two groups: (1) providers, researchers, and public health professionals and (2) all other consumers. SIS's future is in creating an appropriate balance in its efforts to meet the information needs of these various groups. He stated that the emphasis in this meeting would be addressing minority populations and added that the definition of "minority" is evolving and changing.

In outlining the content of the environmental health information databases at NLM/SIS, Dr. Snyder borrowed a term coined by DoD, "CBRNE(S)" ("S" added by Dr. Snyder). Each letter represents a different environmental factor:

**C=Chemical.** Industrial agents, drugs, and household products.

**B=Biological.** Virus, bacteria, fungi, and protozoa.

R=Radiation.

**N=Nuclear.** There are different definitions of "nuclear" among the various federal agencies.

#### E=Explosives.

**S=Social/Behavioral Forces/Factors.** Many social/behavioral forces impact or have the potential to impact the environment.

Dr. Snyder described the methodologies SIS currently employs in disseminating environmental health information and other methods that are under consideration, and posed questions for the TIOP's consideration.

**Factual/bibliographic databases and dictionaries,** including development and maintenance. Other databases are being contemplated and are in various stages of development.

**Images.** What should be the future of images in our information sources? How do they apply to disparities? The Panel could make a significant contribution in this area.

**Research data/information generated in the public or private sector.** This information could be helpful in any outreach or dissemination effort.

Wired vs. wireless. What would it mean to go wireless?

**Search engines, information portals, and one-stop-shopping.** The mission of NLM is organization and dissemination of information, which means pulling together useful information from other organizations. Dr. Snyder sees SIS's role as integrating all this information, as well as appropriately integrating public information with private information. SIS will be presenting the concept of metasearching environmental information within the coming year.

**Various aspects of "interface."** Interface includes graphical and textual elements. Dr. Snyder encouraged discussion of the balance between these two. Information mapping should be considered as a means of augmenting accessibility of information in large, text-based databases. (Refer to <a href="https://www.infotoday.com/newsbreaks/nb020513-1.htm">www.infotoday.com/newsbreaks/nb020513-1.htm</a> for more information.)

Dr. Snyder then discussed the future direction of SIS and the challenges to be faced.

**Technology.** One common and recurring challenge is that technology, as it is developed, sometimes becomes obsolete before it "grows up." When making an investment in a technology, one runs the risk that it will become obsolete.

**Intellectual property rights.** Another issue is that of proper balance between private rights and the public's interest in information. No matter what information domain NLM/SIS is involved in, it must be increasingly concerned about who in the private sector is claiming what as their intellectual property, noting that the publishing houses want to claim an increasing amount of ownership. The American Academy of Arts and Sciences' publication *Daedalus*, in its Spring 2002 issue, addresses the concept of "fencing off" information.

Dr. Snyder also recommended *A Question of Balance: Private Rights and the Public Interest in Scientific and Technical Databases*, published by the National Research Council, Academy of Sciences in 1999. (See www.nap.edu/catalog/9692.html for more information.) Another good resource for addressing this global issue is Creative Commons (http://creativecommons.org).

Dr. Snyder encouraged discussion of marketing federal information in the environmental health arena. In this area, such things as speed, availability, currency, and validity are important evaluative criteria that SIS has developed to decide whether to link to a particular Web site.

**Investigative work.** The NLM's Lister Hill National Center for Biomedical Communication conducts informatics research. NLM's Intramural Programs fund a variety of research efforts in data and text mining (see <a href="www.cs.waikato.ac.nz/~nzdl/textmining">www.cs.waikato.ac.nz/~nzdl/textmining</a>).

Dr. Snyder encouraged the Panel to think about creative ways to use the concept of mining and how to research the impact of NLM's products.

Dr. Snyder noted the importance of SIS thinking of the future in deciding how to lead its outreach efforts. For example, books may in the future be widely available on compact discs (CDs). A CD can hold 3,000 pages of information, but if hardware to read the disk is unavailable, it is useless. Dr. Snyder referred the Panel to the Millennium Project (<a href="www.unmillenniumproject.org">www.unmillenniumproject.org</a>), sponsored by the American Council for the United Nations University, which produces reports annually that provide a context for global thinking and planning. The 2002 State of the Future report (<a href="www.stateofthefuture.org">www.stateofthefuture.org</a>) describes a study that is a good example of building collective intelligence based on a large network across the world. Other information challenges are associated with the subject of toxicology. For example, there are a variety of ways for a toxicologist to accurately and appropriately represent "who they are." There are at least six—and soon to be seven—ways to certify as a toxicologist today and each organization has its own credentialing process, creating conflict in the field. Dr. Snyder stressed the importance of fostering a spirit of collaboration.

Finally, Dr. Snyder mentioned two additional major issues: environmental politics/policy and environmental terrorism. Regarding the first, Walter A. Rosenbaum has written a book titled *Environmental Politics and Policy* (ISBN 1-56802-645-5) that Dr. Snyder highly recommend. For more information about this book, visitwww.cqpress.com.

Regarding environmental terrorism, SIS will be attending a meeting on remedying the deficiencies in data for medical emergencies likely to emerge from chemical/biological warfare. Dr. Snyder cited that Dr. Anthony Fauci, Director, National Institute of Allergy and Infectious Diseases, has been tasked with leading this effort. Dr. Snyder stated that SIS should develop improved and varied ways to gather and disseminate this information.

#### **INTERACTIVE DISCUSSION**

Dr. Henry Lewis, Dean, School of Pharmacy at Florida A&M University, thanked Dr. Snyder for his perspective on how SIS is positioned for the future. Lewis expressed his appreciation for Dr. Snyder's sensitivity to the digital divide in minority communities and institutions. Dr. Lewis stressed the critical role the Panel has played in this arena over the last 11 years and said that Panel members have been able to do more at the university level as a result of their association with NLM and TIOP. The information explosion is hard to keep up with, but the Panel has been very responsive in working with their respective communities.

The Panel's successes have positively affected many communities and institutions and have helped to shape Dr. Lewis' philosophy and decisions. For example, he cited that Florida A&M University started a Ph.D. program in environmental toxicology as a result of its association with this Panel and Dr. Lewis' previous association with Texas Southern University College of Pharmacy. Other examples of the impact of the Panel include the following:

- Florida A&M has developed an Institute of Public Health, which is a major outreach component in public health in the state of Florida. The university's relationships with TIOP and NLM made this possible.
- In Tipton, Georgia, a project called "Liftin' Tipton" empowered the community to assess its own environmental condition. Soon ATSDR and Superfund will provide over five million dollars to remediation there.
- Florida A&M now requires certification as a result of its association with TIOP and networking with the other universities.
- Xavier recently built a new pharmacy building with a huge library.

Dr. Bailus Walker reinforced Dr. Lewis' statements. He added that TIOP has been productive for the NLM and the institutions that have benefited from it, and that the record would show this has been an effective investment. He noted substantial progress in outreach activities and the constant training and upgrading of skills and knowledge by ORISE. Dr. Walker remarked that the next 10 years for TIOP will be just as exciting and challenging as the first 10 years.

#### SIS UPDATE

Martha Szczur, SIS Associate Deputy Director, gave a demonstration of the SIS Web site, noting recent changes and updates. Dr. Snyder stressed the importance of the Panel's effect on groups that have the greatest barriers to getting information, focusing as much as possible on health disparities.

Ms. Szczur began the demonstration with the SIS home page, which illustrates areas SIS is involved in. Throughout the demonstration, there were questions and comments from the Panel. A summary of information relayed during the demonstration follows:

- Toxicology and Environmental Health http://sis.nlm.nih.gov/Tox/ToxMain.html.
- Special Topics in Toxicology and Environmental Health
  <a href="http://sis.nlm.nih.gov/Tox/ToxSpecial.html">http://sis.nlm.nih.gov/Tox/ToxSpecial.html</a>: Provides links to in-depth knowledge in specific areas, such as Arctic health, arsenic (new), Asian-American health (new), and biological warfare.

  A Native American page is also under development. The site offers for each topic background/introductory information, government information resources available (selected based on specific criteria), how to get information from NLM, current concerns, links to related Web sites, etc.
- HIV/AIDS Information
   <a href="http://sis.nlm.nih.gov/HIV/HIVMain.html">http://sis.nlm.nih.gov/HIV/HIVMain.html</a>: Includes the latest information on HIV/AIDS treatment, drugs, clinical trials, and access to journal articles/books/audiovisuals, and other consumer health information.
- TOXNET

<u>http://toxnet.nlm.nih.gov</u>: Databases on toxicology, hazardous chemicals, and related areas. As a result of user feedback, SIS has added the ability to search all the databases. Ms. Szczur demonstrated a search on arsenic, showing the number of hits from each database. Dr. Walker suggested the possibility of looking at diseases and disparities from the perspective of the impact

of environmental factors. For example, exposure to toxic substances is a risk factor in low birth weight. Searches could be conducted based on the identified environmental components. Another suggestion was to consider the relationship between solvents and diabetes. Making these kinds of connections is valuable, even if the risk is only perceived.

#### Haz-Map

http://hazmap.nlm.nih.gov: This database contains information on hazardous agents and their relation to occupational diseases, including type, adverse effects (list of symptoms), diseases are associated with the agent, industrial processes, and activities with risk of exposure (i.e., drinking water from a private well). Links to additional information are also provided.

Dr. Walker pointed out that this information would be very useful, especially since the Supreme Court has just ruled that even if someone fears they will get mesothelioma from asbestos they can sue their employer. There may be other diseases that will fall into this category. Ms. Szczur added that searches can be conducted for major disease categories and jobs/symptoms. Further information can be obtained by highlighting the term on the Web page and clicking the "Search TOXNET" button.

The Haz-Map database targets professionals and is particularly valuable because an affected worker may not be seen by an occupational health professional in the workplace, but will instead go to their primary care provider—who may not make the association. A large number of cases are being brought to non-occupational medical clinics as well.

Comments and suggestions made during the ensuing discussion that followed included the following:

- Include musculoskeletal diseases in this database, as confined spaces are a major factor in occupational health.
- The language used can be a major obstacle because information is often written in a way that most people cannot understand. Additionally, different groups of people use their own words for particular diseases. For example, the African American community refers to diabetes as "sugar." The Panel was encouraged to pass along this kind of information to NLM, as they may know vernacular terms NLM does not and this is valuable information.
- Mechanisms for getting this information exist in the products (MEDLINEplus, for example). Ms. Szczur encouraged everyone, as they use the databases and find situations like this, to send the information to NLM so it can be added.
- TIOP could provide NLM with a dictionary of disparity-related terms, such as "sugar" for diabetes, so they could be incorporated into the databases.
- Informatics research is an area the Panel can explore.

Another issue to consider is what the best approaches are to communicate information (passing out flyers, inviting people into a room for discussion, or hoping the foreman will pass information on to the workers). In some industries, understanding the hazards associated with a particular job is mandatory.

- NLM is striving for a broad spectrum in its outreach. For example, there is a plan to approach some of the major unions in an attempt to get to the actual workers—to target all levels of organizations.
- One of the driving forces to consider is the benefit for the individual for engaging in information seeking. There must be incentives for the employee as well as the employer.

• Dr. Herreno, University of Puerto Rico Medical Sciences Campus, noted that the Hispanic community is at the entry level in this area and is working on the streets. The language barrier needs to be addressed.

The Panel then discussed the accessibility of information that is not peer-reviewed and how to reach consumers with non-traditional approaches. Questions, statements, and suggestions included the following:

- How can information be collected about experiences that increase peer-reviewing? For example, most disaster medical information is not peer-reviewed and not found in journals. The term for this kind of information is "grey literature."
  - ➤ Grey literature is that which is produced by government, academics, business, and industry—in print and electronic formats—but not controlled by commercial publishers. Grey literature includes, but is not limited to, reports, theses, conference proceedings, technical specifications and standards, non-commercial translations, bibliographies, technical and commercial documentation, and official documents not published commercially.
- Consider how to reach new audiences.
- Find ways to capture non-traditional sources of experience information. One example is sanitation workers in Washington, D.C.
- "Lessons learned" experiences (another example of grey literature).
- Determine if any information is better than no information. For example, should people be given quality information because when they use it, it might impact their health?
- Is mercury in fish a factor in cardiovascular problems? Experts disagree.

NLM does not make judgments about particular findings; the only judgments made are at the level of whether to include a particular journal. There are no judgments on individual studies. A note is made when a study is withdrawn.

Dr. Snyder wondered if criteria applied across the board is applied in the same way to environmental health. The Lister Hill committee has developed criteria, but this does not apply to conflicting information. The Panel should consider how to help the public deal with conflicting information.

It is one thing to make information available and another to make evaluative remarks about it. Private and professional roles must be distinguished. Evaluative statements can be made as long as it is clear they are not the opinions of government.

The New York Academy of Medicine publishes the *Grey Literature Report* in which findings not published standard journal literature are identified. The Panel could explore what parts, if any, of the grey literature should be provided to the public. Also worth considering is that even information that isn't peer-reviewed can be relevant. For example, one of the facts of the future for the Panel is the question of involvement in public policy information. Although this kind of information is not peer-reviewed, a judge's decision is quite authoritative. Authoritativeness needs to be considered in a broader way.

#### • ALTBIB

<u>http://toxnet.nlm.nih.gov/altbib.html</u>: Alternatives to using live vertebrates in biomedical research.

#### • Tox Town

http://toxtown.nlm.nih.gov: An introduction to toxic chemicals and environmental health risks that the consumer may encounter in everyday life and everyday places.

The inspiration for Tox Town was to find a way to make the subject of toxicology and areas of exposure more fun and compelling. The result has developed into an engaging tool with animation and sounds that might prompt some users to stay longer. Use of a simple language also helps hold visitors.

There were many comments/suggestions during this dialogue, including:

- Tox Town's graphic interface is motivating.
- Some of the feedback received has been that it "doesn't look like my town." A "large city" scene is already being developed.
- Include a "work town" with offices, stores, etc.
- NIOSH can provide information from the transportation industry, construction industry, convenience stores, gas stations, etc.
- Determine the relevant graphical interfaces to portray minority disparities.
- To target minority groups, the design might portray "the Hood" and include cars with hydraulics, etc.
- Include oil refineries.
- Use real pictures when possible instead of animations.
- Try incorporating an online focus group to obtain feedback.
- Charles Drew University of Medicine and Science has set up a Jeopardy-style game, which has resulted in substantial differences in performances.
- Tox Town will be an excellent way to communicate information to people who don't
  have health insurance. It can be used in kiosks in community health centers. Some of this
  is already being done.
- A new plan for Tox Town is to provide an animated mystery associated with a particular environmental health issue and have different outcomes based on what the user chooses to do (i.e., "make up your own ending" stories).
- Ms. Danner, Oglala Lakota College, suggested a different picture for the Native American, showing flat land with very few trees, barbed wire fences, and livestock consisting of cattle, horses, or pigs—but no sheep (there is a tribal injunction against sheep). She also commented that an effective way to give this information out on the reservation is at a Pow-Wow. There are not many computers in the Lakota community. A train-the-trainer class could be offered for the people who travel the circuit doing tribal dancing to learn how to talk about it.
- Additional Tox Town scenes already being developed are a Texas/Mexico border town and a California beach town. The possibilities are limited only by the imagination.
- Use an interactive program, so the computer could "talk" back. This would be good for the older generation who is unfamiliar with computers.

The Panel was also asked to consider the scope of its outreach. Comments included the following:

- Efforts to address disparities should target all generations. A young audience is appropriate, but it is just as important to help the elderly focus on quality of life.
- It would be helpful to include information on radiation exposure, as the Native American population is highly exposed to ionizing radiation. Ms. Danner added that, on the reservation, there is a certain feeling of fatalism, a learned helplessness that keeps residents from leaving. Danner added that this population would need help using the information and incorporating it into their traditional value system.
- Another aspect of radiation exposure discussed was the misunderstanding about irradiated foods. There is a bill under consideration about putting irradiated meats in the school lunch program. Some sources say irradiated meat is not a risk, but another source says radiation causes carcinogens in the fat. The public is confused about the difference between food being "irradiated" and being radioactive. An effort should be made to clarify these terms.

#### DEMONSTRATIONS OF NLM RESOURCES

Cassandra Allen reviewed changes in the NLM databases, recommending that one always begin at the NLM home page (<a href="www.nlm.nih.gov">www.nlm.nih.gov</a>) because everything can be reached from that page.

#### MEDLINE/PubMed

http://pubmed.nlm.nih.gov: Consumer health information about conditions, diseases, wellness, prescription and over-the-counter drugs, help with finding physicians, clinics, hospitals and current health news.

The latest change to MEDLINE/PubMed is the addition of icons to the search results. Ms. Allen demonstrated with a search on "environmental health disparities." The LinkOut feature enables those working for institutions that receive an electronic version of a journal to obtain access to the journal. Another change is the new "Send to" feature for saving text.

During this demonstration, questions were raised and issues discussed regarding the use of special terms in the NLM/SIS databases, measuring the use of the databases, how the new privacy regulations will affect the healthcare industry, the use of genetically modified organisms, and environmental disparities on the international level.

• Special terms. There is a need to improve the environmental health terminology in SIS's Universal Medical Language System (UMLS), and the TIOP can have an impact in the use of special terms. However, Ms. Dutcher advised that the criteria for getting new terms into MeSH are strict. Terms submitted need to be part of a "set" of terms. This task would require an organization to develop and submit the terminology, maintain it, and report it to NLM. This is an issue for the future.

#### Measuring database use.

 For PubMed and MEDLINEplus, the number of hits is measured and the information obtained drives decisions. SIS also has a tool that tracks data on individual pages. In TOXNET, search terms are tracked. Unsuccessful search terms are recorded. Surveys of

- MEDLINEplus users, TOXNET users, PubMed users, and NLM homepage users have been conducted. Any kind of survey must first have Office of Management and Budget (OMB) clearance.
- o There has been a definite link between exposure in the media—as well as scientific announcements—and use of the databases. This has been especially true for MEDLINEplus.
- Outcome—what people do with the information—is also measured. NLM has identified 10-12 different categories of users from the surveys it has conducted and has interviewed samples of those groups. Toxicologist researchers were the most frequent type of user and the primary use for the databases was research. A suggestion was made to follow up with these researchers.
- o Dr. Snyder pointed out that evaluative research in informatics is in its infancy and all federal agencies need to improve their handling of this issue. The medical field has privacy issues as an added factor. Hopefully, the end result is improved health, but this is impossible to measure. Educating the government is key.
- **Privacy regulations.** HIPAA (Health Insurance Portability and Accountability Act of 1996) will go into effect this year. The complexity of these regulations is such that people are over-cautious, making exchange of information more difficult. Healthcare facilities and related businesses are going to be impacted, and there is a limit to what a federal agency can do to monitor results. Dr. Snyder referred the group to information on the Web at <a href="www.hhs.gov/ocr/hipaa">www.hhs.gov/ocr/hipaa</a> and <a href="www.cms.hhs.gov/hipaa">www.cms.hhs.gov/hipaa</a>.
- **Genetically modified organisms.** The EPA is currently dealing with the issue of making plants insect-resistant. The FDA is handling the food issue, but there's a lot of confusion about the safety of these products. Europeans say they don't want to use genetically modified organisms, which has an impact on world opinion. For example, although its population is starving, Zimbabwe has adopted the European perspective and will not accept genetically modified foods.
- International environmental disparities. Should NLM/SIS or some larger federal agency deal with the informatics of this issue? Dr. Walker suggested that all issues are now global. With two million people crossing international boundaries every day, it is difficult to think of a health subject that does not have international implications. Ms. Block told about a rehabilitative clinic in Nairobi that uses Google to find health information. They had not been to the National Library of Medicine Web site. Dr. Walker suggested that the international issue should be a long term goal since the Panel currently has enough other goals.

#### **MEDLINE plus**

http://medlineplus.gov: Consumer health information about conditions, diseases, wellness, and prescription and over-the-counter drugs; help with finding physicians, clinics, and hospitals; and current health news. MEDLINEplus is also available in Spanish.

Ms. Allen demonstrated the new look for **MEDLINEplus**, pointing out the differences in the retrieval display. She then highlighted the interactive health tutorials by demonstrating the Carpal Tunnel Syndrome slide show with speech.

#### **NIH Senior Health**

<u>http://nihseniorhealth.gov</u>: An easy-to-read Web site for older adults, developed by the National Institute on Aging and NLM. Topics include "Caring for Someone with Alzheimer's," which includes information on home care with many video clips interspersed throughout.

#### **Databases Under Development**

**ToxSeek** is a metasearch engine for environmental health, and uses geographical information systems to map chemicals in the environment, identify chemicals and facilities in a particular area, and more. A goal of ToxSeek is to overlay information from other sources, such as census data and minority information to show whether there is a heavy minority population being affected by particular chemicals in the environment. The site will include links to HSDB and ATSDR.

The **Household Products** database is designed to help consumers answer questions regarding the chemicals contained in the products they use, percentages in specific brands, manufacturers, potential health effects, and links to information in other NLM toxicology-related databases.

#### DRAFT STRATEGIC PLAN

Dr. Melvin Spann, NLM consultant and TIOP Executive Secretary, lead the discussion. The ideas expressed in the proposed objectives and mission statement represent input from the TIOP assessment study conducted by Mr. John Scott that included notes from conversations, meetings, phone calls with Dr. Walker, and input from most of the TIOP members individually, and provide a backbone for establishing a new strategic direction for the Panel.

The new direction proposed by Dr. Spann is to restructure the Panel to cover health disparities, consumer health, and community health outreach. These are activities and issues of concern to NLM, NIH, and the Department of Health and Human Services, and it is important for the Panel's goals to be consistent with these organizations.

#### PROPOSED OBJECTIVES

#### 1. Expand the core of participating institutions

Minority-serving educational institutions that have health-related programs—such as nursing, allied health, public health, etc.—could be added to the Panel. Examples are United Negro College Fund Special Programs (UNCFSP) grant awardees, such as Albany State or Norfolk State and Voorhees College, which would like to serve as a focal point for environmental health outreach in South Carolina, including the Gullah population. The suggested limit on the number of people for the group is 20.

The TIOP Executive Committee will review a matrix of minority schools and health-related programs and determine what schools should be a part of the group. This might mean displacing some current schools or choosing representation from some other part of a particular institution. This will be dealt with by the Executive Committee. One scenario suggested is that the current institutional membership could remain the same for two years for

continuity, and schools originally a part of this outreach effort would have a two-year rotation. Schools added to the Panel later (Hampton, University of Puerto Rico, and Lakota) would have a three-year rotation. New schools would have a four-year rotation. The Panel chair should come from within the Panel and, in order to be fair, some will have to be brought in and others rotated off. The Panel could meet twice per year.

The Executive Committee could be composed of the chair, Dr. Henry Lewis, who would also serve as chair of the Executive Committee; a senior advisor (Dr. Bailus Walker); an executive secretary (Dr. Melvin Spann); and an SIS representative(s). The associate director of SIS would be the primary SIS representative, but have additional help. An added panel member would offer an opportunity to add diversity (for example, a female to balance mostly males on the Executive Committee).

The Panel would adopt a new name to reflect its new direction. One suggestion is "Environmental Health Information Outreach Panel (EnHIOP)." The name should represent all aspects of the Panel's activities.

It was suggested that meeting attendance be optimized by having a primary and an alternate representative named so that at every meeting every institution could participate in the discussion. It is important to clarify that the person is not only representing the institution but also bringing an area of expertise to the table. The dissemination of information at the institutions is also important.

New representatives should be given an information package so they know what is expected of Panel members. The institution should promote the use of NLM resources through various channels. For example, Dr. Copeland, Howard University College of Medicine, has changed the curriculum at Howard so that incoming students are immediately exposed to NLM resources. The goal is wide-spread institutional awareness and use of the NLM databases, including higher level administrative and academic individuals at the institutions. Distribution of annual reports to appropriate persons at each institution is one way to do this.

#### 2. Strengthen institutional partnerships

It would help to "institutionalize" the new name of the Panel. The Panel needs to be more aggressive about this.

#### 3. Develop or strengthen relations with community-based and faith-based organizations

Although there has been activity in this area, much more can be done.

#### 4. As a group, become more involved in professional meetings/public forums

For example, Ms. Allen organized a TIOP presentation at the Medical Library Association annual meeting that Dr. Spann and Dr. Copeland will co-present. Dr. Walker and Dr. Spann will be writing a paper on TIOP for publication (history, impact, etc.), with the kickoff in April.

#### 5. Promotion of NLM resources by individual Panel members

Panel members should organize/facilitate activities to promote NLM resources. Panel members could ensure, for example, that someone at their institutions goes into the community and teaches people how and when to use HSDB.

The Panel should has or seminars and conferences to expose Panel members and other institutional representatives to state-of-the-art science information technology relevant to health issues of concern to this audience. The Executive Committee would take the lead on this. Dr. Walker suggested that if the Panel is expected to take on these additional activities and invest additional time, NLM should provide additional compensation. For training activities in the communities, training materials should also be provided. ORISE has a wealth of training materials they have used for 12 years now and have continuously updated. ORISE could also help train these trainers.

More consistent use of the TIOP listserv would be helpful, especially as a resource awareness tool to see grant opportunities and links to other areas that would be relevant.

The Panel should be more proactive in positively affecting the health and well being of minority communities. It is the responsibility of HBCUs to produce the minority students who will serve the minority community. It is also the responsibility of HBCUs to go beyond the walls of the university and interact with the communities, to be a conduit of information to the minority community.

#### PROPOSED MISSION STATEMENT

"The mission of the Environmental Health Information Outreach Panel is to enhance the capacity of minority-serving academic institutions to reduce health disparities through the access, use, and delivery of environmental health information on their campuses and in their communities.

Assumptions: Environmental health refers to the impact of chemical, microbial, physical, and radiological agents on the health of living organisms.

Minority serving educational institutions are those served by programs funded under Title III Historically Black Colleges and Universities, American Indian Tribally Controlled Colleges and Universities, Alaska Native and Native Hawaiian Serving Institutions, and Title V Hispanic Serving Institutions. (Reference: U.S. Dept. of Edu., <a href="https://www.ed.gov/offices/OPE/HEP/idues">www.ed.gov/offices/OPE/HEP/idues</a>)."

#### DISCUSSION

Dr. Henry Lewis led a detailed discussion following the presentation of the proposed objectives and mission statement/assumptions. Highlights of that discussion follow.

#### **Mission Statement**

• Regarding "access" and "delivery" of information, the Panel agreed that there is an implication of "translation" of information, but not "interpretation." An example would be translating studies of arsenic into terms the community can understand—the language should be explicit and readable at the eighth grade level.

- A major factor discussed is that when the director testifies on Capitol Hill and ask for appropriations, what does he or she need to help legislators understand the information that the library accumulates? It is important that information be disseminated in a culturally and linguistically appropriate fashion.
- The mission statement should be broad, clear, and crisp and be consistent with NLM's goals and objectives. Max Lum suggested the importance of considering the desired outcome and what information people need to make meaningful decisions.
- Dr. Bayorh, Morehouse College of Medicine, stressed the importance of having core discussions, an element that has been missing. Medical curriculums are not as easy to change as one might think. Dr. Spann pointed out that incorporation of NLM resource information into a lecture is easy to do and doesn't require changing the curriculum. Incorporation can be achieved in the context of the particular course. Therefore, "curriculum change" should not be used.
- Ms. Dutcher pointed out that the "campus" is one physical focus and the "community" is another, and this should be clearly stated.
- Other comments/suggestions that were made included:
  - Change "delivery" to "dissemination," a word frequently used in libraries.
  - "Enhancing capacity" are well chosen words.
  - Discover areas in which information is lacking and acquire additional information in those areas.
- Include "sociocultural" as an assumption. There was disagreement on the point of including the word "radiological." People outside of the scientific frame of reference may not include "radiological" in "physical," which is a good reason to include "radiological." It is also important to be scientifically accurate and to be consistent with the literature.

#### **Objectives**

- Include something on health disparities.
- Adopt NLM's mission of information management and dissemination.
- Provide guidance to NLM in a proactive way regarding the needs of the minority population—what people in the minority community are concerned about.
- Add sponsors (other government agencies) as a way of increasing funding for the TIOP's activities. This could work if the mission statement includes objectives of other government agencies. They would not have to be voting members.
- Participate in professional meetings and community meetings as a way to increase the visibility of TIOP.
- Encourage researchers to cite TIOP as a source to increase exposure and cultivate recognition of TIOP. Additionally, it was decided that Dr. Spann and Dr. Walker would collaborate on a paper on TIOP and get it published to help give the Panel more visibility.
- Take advantage of the braintrust that has developed in the TIOP to have an impact on public opinion in a public advocacy role, i.e., for protecting minority populations. A statement of public support and awareness from the group would be more compelling than that from any one university in the group.

- Promote the TIOP as composed of top experts in environmental health in the minority community for greater impact.
- Enhance capacity building and develop a tool to measure progress.
- Sponsor seminars/conferences on specific topics as a way of exposing people to the NLM resources. It is important to organize this around a subject of interest to the community that would motivate them to attend. One example is to produce a paper on a current environmental health topic and hold a morning session during minority health month to present it.

The Panel discussed whether any recurring forum for addressing minority health disparities already exists. Dr. Walker cited the National Black Economic and Environmental Justice Coordinating Committee, which has an ongoing activity. What TIOP could do is create a "platform" and rotate the site among the member institutions. Several suggestions were made, including the following:

- Focus attention on the relevant communities to have more impact on the campuses.
- Use signage to promote name recognition.
- Plan a two-day meeting, with the first day to be closed. On the second day, leaders of other institutions and related communities could be invited to enter into the discussion. The host of the meeting would identify leaders in their community to come to the second day. If there are two TIOP meetings per year, the second meeting could be in the field in order to invite people who don't normally get exposure to TIOP, including representatives from other HBCUs and MEIs.

Ms. Allen cited an activity to promote TIOP at meetings that have already been planned, one at the Medical Libraries Association (MLA) annual meeting.

- A panel discussion on TIOP will be presented at the Medical Libraries Association annual conference, where Dr. Spann will talk about history, Dr. Copeland a specific project, and Dr. Lewis about TIOP's future.
- NLM's health resources will be discussed at the American Library Association meeting in June.

An added goal of addressing librarians is to broaden the awareness of the scope of what librarians could be doing in their communities. When any health issue develops, it is NLM's hope that people will call their local medical library (hospital library, academic health sciences library, etc.). Dr. Snyder indicated that many people still associate libraries with print material. Therefore, there is a need for libraries to promote their electronic resources.

Additional suggestions regarding the involvement of libraries included the following.

- This would be a good recommendation to Homeland Security. The Patriot Act allows for FBI and police to go into a library and obtain records of who is doing what in the library, and people in the library are not allowed to tell anyone. So what you have been searching in the library could target you. Libraries have protected peoples' rights for years but can no longer do that under the Patriot Act. The Patriot Act lowers the threshold of accessing personal information in the context of a public library. It has not yet been determined exactly what degree of probable cause will be necessary to override the library's protection of information.
- Libraries could develop a proactive plan of community involvement. For example, the library at Florida A&M played an integral role in a city-wide drill that involved almost 5,000 people.

• Ms. Danner, Oglala Lakota College (OLC), pointed out that on the reservation, physical use of a library is out of the reach of most, and wondered if NLM could do anything to address this issue. For example, OLC has only one library in 5,000 square miles. The adjacent reservation is in the same situation. Could SIS help develop public service announcements? Native Americans on the reservation have practically no information that comes to them in an organized fashion. There's very little understanding on the reservations, for example, of what the response to smallpox is all about. This is information disparity. Dr. Walker pointed out that misunderstanding and confusion is present everywhere about smallpox. Ex: Philadelphia's major medical institutions disagree on their recommendations regarding smallpox.

Lastly, the Panel discussed the relevance of dietary issues in addressing health disparities. Diets of all minorities are a factor in disparities. Dr. Lewis remarked that if diet was addressed, disparities could be cut in half within a decade in African Americans. Other examples include the following:

- Food is a vector of environmental contaminants.
- Salt is a major contributor to hypertension.
- Commodities—when foods are imposed upon a group, such as the commodities on Native
  American reservations—limit access to many health foods. One grocery store can serve an entire
  reservation. A paper on Native Americans and commodities could be written to include
  information with the outcome that the commodities could change.
- Food excess is a form of toxicity. The fundamental principle of toxicology is that the dose makes the difference.
- Endocrine toxicology.
- There is good evidence that cooking at high temperatures causes the accumulation of acrylamide.

#### **CONCLUSION**

In conclusion, Dr. Snyder suggested that the Panel needs to evolve because there are a variety of needs in the minority communities requiring a variety of solutions. Mr. Scott added that it is important to represent the collective interests of minorities from the minority perspective.

Dr. Lindberg and Dr. Snyder then presented certificates of appreciation to each of the TIOP members present. Dr. Walker was presented with a special gavel plaque in honor of his 10 years of service as TIOP Chairman, and Dr. Lewis, as the new TIOP Chairman, was presented with a gavel that will be passed on to each successive chairman of the Panel.

Dr. Lindberg gave closing remarks and Dr. Walker cited Dr. Lindberg's support of the Panel over the years.

## NATIONAL LIBRARY OF MEDICINE TOXICOLOGY INFORMATION OUTREACH PANEL

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2002-2003



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