

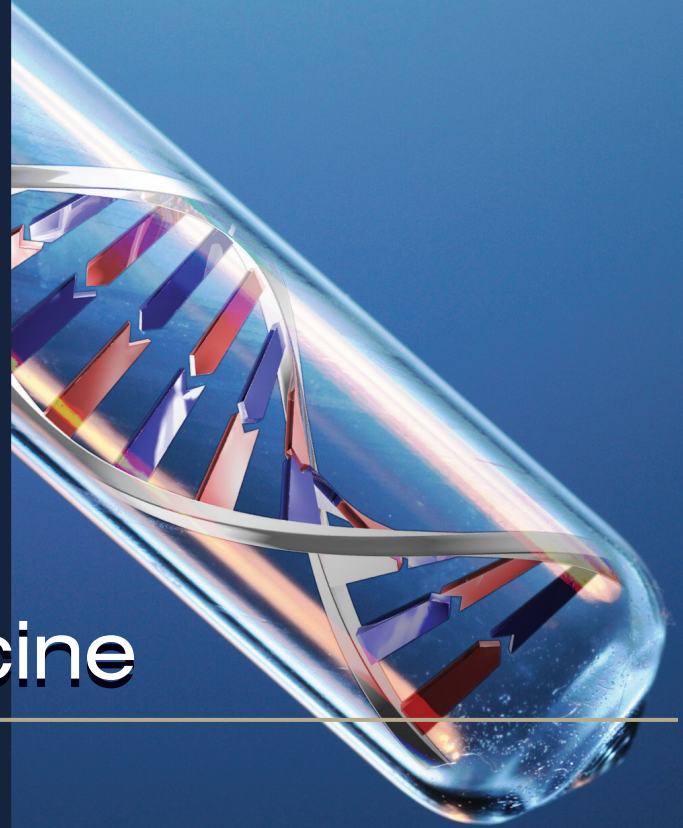


U.S. National Library of Medicine®

Environmental Health Information Partnership

Transition, Challenges, and Opportunities of Precision Medicine

Proceedings
April 11–12, 2017



**NATIONAL INSTITUTES OF HEALTH
NATIONAL LIBRARY OF MEDICINE®**

**ENVIRONMENTAL HEALTH
INFORMATION PARTNERSHIP**

PROCEEDINGS

BETHESDA, MARYLAND

APRIL 11–12, 2017

***TRANSITION, CHALLENGES, AND OPPORTUNITIES
OF PRECISION MEDICINE***

PREPARED FOR
DIVISION OF SPECIALIZED INFORMATION SERVICES
NATIONAL LIBRARY OF MEDICINE

PREPARED BY
HEALTH, ENERGY, AND ENVIRONMENT
OAK RIDGE ASSOCIATED UNIVERSITIES

This document was prepared for the **Division of Specialized Information Services, National Library of Medicine, National Institutes of Health** by the Oak Ridge Associated Universities (ORAU)

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NEWEST MEMBERS OF THE ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP

The National Library of Medicine® (NLM) Environmental Health Information Partnership (EnHIP) is a collaboration between NLM and Historically Black Colleges and Universities (HBCUs), a Predominately Black Institution (PBI), Hispanic-Serving Institutions (HSIs), Tribal Colleges and Universities (TCUs), an Alaska Native-Serving Institution, and a community college. The newest institutions to participate in EnHIP are Navajo Technical University and The University of New Mexico.



Navajo Technical University

Navajo Technical University (NTU) is one of the largest tribal colleges and universities in the United States, servicing students across three campuses in Crownpoint, New Mexico, and Chinle and Teec Nos Pos, Arizona. NTU was founded as the Navajo Skills Center in 1979 with the specific aim to address and reduce unemployment on the Navajo Nation. In 1985, the Skills Center became the Crownpoint Institute of Technology, and in 2006 it became Navajo Technical College. NTC added its first baccalaureate degree in 2011, and two years later, with the approval of the Navajo Nation Council, it be-

came NTU after it switched its focus to higher levels of educational obtainment and research.

Today, NTU offers 10 baccalaureate degrees and the Navajo Nation's first graduate degree, offering students a unique blend of Western education with traditional Navajo culture and language. While NTU transitioned into a four-year university in 2013, it has maintained its identity as a technical institution and offers 22 certificates and 17 associate degrees. Many of the associate degrees serve as feeder programs into undergraduate degree programs at NTU. NTU is accredited under the Higher Learning Commission, and it maintains special accreditation under national associations like the American Culinary Federation and the National Center for Construction Education and Research.

The University of New Mexico



Founded in 1889, The University of New Mexico (UNM) now occupies nearly 800 acres near old Route 66 in the heart of Albuquerque. The campus buildings echo nearby Pueblo Indian villages with their distinct Pueblo Revival architecture.

As a Hispanic-serving institution with an enrollment of 32,000 students, UNM represents a cross section of cultures and backgrounds. The University was recognized by Hispanic Business Magazine with rankings in the top 10 for the School of Law, Anderson School of Management, School of Engineering, and School of Medicine. UNM's libraries, museums, galleries, and performance spaces are rich cultural resources for the state.

The University of New Mexico Health Sciences Center (UNM HSC) is an integral part of UNM. Founded in 1994, it fulfills a unique role as the state's only academic health center. UNM HSC is committed to addressing health and educational disparities through faculty diversity, linguistic and cultural competence, community engagement, and leadership on issues of inclusion and equity.

UNM HSC offers training in all health professions, translates research and discoveries into clinical practice, and delivers clinical care accessible to state residents of every income level. Education is central to UNM HSC's mission. The School of Medicine, the College of Nursing, the College of Pharmacy, and the College of Population Health collaborate closely with working practitioners in their fields and work in partnership with UNM hospitals and clinics. UNM HSC's research mission has a long history of innovation and scientific breakthroughs that have spurred economic growth and social improvement throughout the state. The research enterprise has seen dramatic growth in sponsored research, from \$45 million in FY 1998 to \$165 million in FY 2016.

HISTORY OF THE NATIONAL LIBRARY OF MEDICINE



In 1836, the library belonging to the U.S. Army Surgeon General was a small collection of medical books on a single shelf. Now known as the National Library of Medicine® (NLM), it is the world's largest biomedical library, with a collection of more than 28 million items in more than 200 languages.

This unique institution is about much more than books and journals. NLM information services and research programs serve the world by supporting scientific discovery, clinical research, education, health care delivery, public health response, and the empowerment of people to improve their personal health.

The Library has evolved from that modest shelf of books into a 21st-century facility committed to the innovative use of computing and communications, including data science, to enhance effective public access to understanding and discovery in human health.



National Library of Medicine®

ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP

Theme: Transition, Challenges, and Opportunities of Precision Medicine

Lindberg Room, Mezzanine, Bldg. 38

April 11–12, 2017

Patricia Matthews-Juarez, PhD, Presiding

AGENDA

TUESDAY, APRIL 11, 2017

8:00 a.m. – 8:25 a.m.	Registration
8:25 a.m. – 8:30 a.m.	Meeting Opening and Welcome Patricia Matthews-Juarez, PhD Chairman, EnHIP
8:30 a.m. – 9:05 a.m.	Report from NLM Director Patricia Flatley Brennan, RN, PhD, MS Director, National Library of Medicine
9:05 a.m. – 9:15 a.m.	Discussion and Q&A Facilitated by Patricia Matthews-Juarez, PhD
9:15 a.m. – 9:25 a.m.	Introductions Patricia Matthews-Juarez, PhD
9:25 a.m. – 10:20 a.m.	Keynote Address: <i>All of Us</i>SM Research Program, Precision Medicine Initiative® Joni L. Rutter, PhD Director, Scientific Programs, <i>All of Us</i> SM
10:20 a.m. – 10:30 a.m.	Discussion and Q&A Facilitated by Sandra Harris-Hooker, PhD
10:30 a.m. – 10:40 a.m.	BREAK
10:40 a.m. – 11:15 a.m.	Open Data Science: Promising Directions and Current Challenges Audie Atienza, PhD Senior Fellow, ICF

**NATIONAL LIBRARY OF MEDICINE
ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP
Lindberg Room, Mezzanine, Bldg. 38**

11:15 a.m. – 11:30 a.m.	Discussion and Q&A Facilitated by Paul B. Tchounwou, ScD, MSPH, MSc
11:30 a.m. – 12:00 p.m.	Online Resources from the National Library of Medicine Laura Bartlett, MLS Technical Information Specialist Specialized Information Services, NLM
12:00 p.m. – 1:10 p.m.	LUNCH (boxed lunches)
1:10 p.m. – 1:30 p.m.	EnHIP Group Picture Ernie Branson, Photographer, NIH History of Medicine Reading Room, Bldg. 38
1:30 p.m. – 2:05 p.m.	African-American Pharmacogenomics: Where Are We Now? Minoli Perera, PharmD, PhD Professor, Northwestern University, School of Pharmacy
2:05 p.m. – 2:15 p.m.	Discussion and Q&A Facilitated by Michael Thompson, PharmD, BCNSP
2:15 p.m. – 3:15 p.m.	Spheres of Ethics in Research Rueben C. Warren, DDS, DrPH, MDiv Director, National Center for Bioethics in Research and Health Care Tuskegee University
3:15 p.m. – 3:30 p.m.	Discussion and Q&A Facilitated by Doris Withers, EdD
3:30 p.m. – 3:45 p.m.	BREAK
3:45 p.m. – 4:00 p.m.	Farewell Remarks Betsy L. Humphreys, MLS Deputy Director, NLM
4:00 p.m. – 4:25 p.m.	EnHIP Outreach Awards Presentation Stephanie Bauer, PhD, University of Alaska Anchorage
4:25 p.m. – 4:45 p.m.	Report from EnHIP Chairman Patricia Matthews-Juarez, PhD
4:45 p.m. – 5:00 p.m.	Wrap-up and Day 2 Overview Patricia Matthews-Juarez, PhD

**NATIONAL LIBRARY OF MEDICINE
ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP
Lindberg Room, Mezzanine, Bldg. 38**

AGENDA

WEDNESDAY, APRIL 12, 2017

- 8:30 a.m. – 8:45 a.m. Registration
- 8:45 a.m. – 9:00 a.m. **Welcome and Introductions**
Patricia Matthews-Juarez, PhD
Chairman, EnHIP
- 9:00 a.m. – 9:30 a.m. **PAHO’s Health Initiatives Commemorating the United Nations
International Decade for People of African Descent (2015–2024)**
Sandra del Pino
Regional Advisor on Cultural Diversity
Pan American Health Organization (PAHO)
- Introduction and Discussion by John C. Scott, MS
Director, Center for Public Service Communications
- 9:30 a.m. – 10:15 a.m. **Update on Minority Health, Health Disparities Research,
and Funding Programs**
Nancy Breen, PhD
Economist, Office of the Director
Michael H. Sayre, PhD
Branch Chief
National Institute on Minority Health and Health Disparities, NIH
- 10:15 a.m. – 10:30 a.m. **Discussion and Q&A**
Facilitated by Patricia Matthews-Juarez, PhD
- 10:30 a.m. – 10:40 a.m. BREAK
- 10:40 a.m. – 11:15 a.m. **EnHIP Outreach Awards Presentations**
- João Ferreira-Pinto, PhD, The University of Texas at El Paso
 - Wansoo Im, PhD, Meharry Medical College
 - Charles (Chuck) Woeppel, MBA, Meharry Medical College
- 11:15 a.m. – 11:50 a.m. **Update on the National Oceanic and Atmospheric Administration**
Juli M. Trtanj, MES
Director, Oceans and Human Health Initiative
National Oceanic and Atmospheric Administration
- 11:50 a.m. – 12:00 p.m. **Closing Remarks**
Patricia Matthews-Juarez, PhD

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL LIBRARY OF MEDICINE®**

**PROCEEDINGS OF THE ENVIRONMENTAL HEALTH
INFORMATION PARTNERSHIP (ENHIP) MEETING
April 11–12, 2017**

The Environmental Health Information Partnership (EnHIP) convened on April 11, 2017, at 8:00 a.m. in the National Library of Medicine (NLM) Lindberg Room, National Institutes of Health (NIH), Bethesda, Maryland. The theme of the meeting was “Transition, Challenges, and Opportunities of Precision Medicine.” Chairman Dr. Patricia Matthews-Juarez, Professor and Vice President of Faculty Affairs and Development, Meharry Medical College, presided. Representatives convened again April 12, 2017, at 8:30 a.m. in the Lindberg Room until adjournment at 12:30 p.m.

ATTENDEES

Representatives from Participating Institutions

Dr. Ann Barbre, Xavier University of Louisiana
Ms. Dolores (Dee) E. Caffey-Fleming, Charles R. Drew University of Medicine and Science
Mr. Steven Chischilly, Navajo Technical University
Dr. Robert L. Copeland, Jr., Howard University
Dr. João Ferreira-Pinto, The University of Texas at El Paso
Dr. Sandra Harris-Hooker, Morehouse School of Medicine
Dr. Diógenes Herreño-Sáenz, University of Puerto Rico
Dr. Jannett Lewis-Clark, Tuskegee University
Mr. Phillip C. (Cody) Marshall, Haskell Indian Nations University
Dr. Patricia Matthews-Juarez, Meharry Medical College
Dr. Judith Mazique, Texas Southern University
Dr. Arlene Montgomery, Hampton University
Dr. Milton A. Morris, Benedict College
Dr. T. Joan Robinson, Morgan State University
Dr. Cheryl Taylor, Southern University at Baton Rouge
Dr. Paul B. Tchounwou, Jackson State University
Dr. Michael Thompson, Florida A&M University
Dr. Robert Valdez, The University of New Mexico
Dr. Doris Withers, Medgar Evers College, City University of New York
Ms. Jill Ziemann, Colorado Mountain College

Alternate Representatives

Dr. Stephanie Bauer, University of Alaska Anchorage
Ms. Kelli Craven, Oglala Lakota College

Consultant to the EnHIP

Mr. John C. Scott, Center for Public Services Communications

Speakers

Dr. Audie Atienza, ICF International
Ms. Laura Bartlett, Division of Specialized Information Services, NLM
Dr. Nancy Breen, National Institute on Minority Health and Health Disparities, NIH
Dr. Patricia F. Brennan, Director, NLM
Ms. Sandra del Pino, Pan American Health Organization
Ms. Betsy L. Humphreys, Deputy Director, NLM
Dr. Wansoo Im, Meharry Medical College
Dr. Minoli Perera, Northwestern University
Dr. Joni Rutter, Science Outreach and Policy, NIH
Dr. Michael H. Sayre, National Institute on Minority Health and Health Disparities, NIH
Ms. Juli Trtanj, National Oceanic and Atmospheric Administration
Mr. Charles Woepfel, Meharry Medical College

Invited Guests

Mr. Hunter Jones, National Oceanic and Atmospheric Administration
Dr. Yvette Myrick, Colorado Mountain College
Dr. Kimberlei Richardson, Howard University
Dr. Kim Sydnor, Morgan State University
Ms. Sandra Talley, Nuclear Regulatory Commission

NLM Staff

Mr. Julian Argoti, Division of Specialized Information Services, NLM
Ms. Lisa Boyd, National Network Coordinating Office, NLM
Ms. Florence Chang, Division of Specialized Information Services, NLM
Mr. James Charuhas, Division of Specialized Information Services, NLM
Ms. Kathel Dunn, Division of Library Operations, NLM
Ms. Cynthia Gaines, Division of Specialized Information Services, NLM
Ms. Jeanne Goshorn, Division of Specialized Information Services, NLM
Ms. Shannon Jordan, Division of Specialized Information Services, NLM
Ms. Janice E. Kelly, Division of Specialized Information Services, NLM
Ms. Franda Liu, National Network Coordinating Office, NLM
Ms. Nicole Scott, Division of Specialized Information Services, NLM
Ms. Amanda Wilson, National Network Coordinating Office, NLM
Dr. Fred Wood, Office of Health Information Programs Development, NLM

ORAU Staff

Ms. LaFrancis Gibson, Oak Ridge Associated Universities
Ms. Linda Lange, Oak Ridge Associated Universities

Day 1

I. Meeting Opening and Welcome

EnHIP Chairman Dr. Patricia Matthews-Juarez, Professor and Vice President of Faculty Affairs and Development, Meharry Medical College, opened the meeting on April 11, 2017, at 8:00 a.m. in the National Library of Medicine (NLM) Lindberg Room, National Institutes of Health (NIH), Bethesda, Maryland. The theme of the meeting was “Transition, Challenges, and Opportunities of Precision Medicine.”

Dr. Patricia Matthews-Juarez welcomed attendees and thanked Ms. Janice E. Kelly and Ms. Cynthia Gaines for their efforts in developing a meeting with high interest and outstanding attendance. For the first time in many years, representatives for all 22 member schools were at the meeting. Priority topics were precision medicine, biomedical informatics, data science, diverse workforce development, and patient-centered care.

II. Report from NLM Director

Dr. Patricia Flatley Brennan, Director, National Library of Medicine, thanked representatives, speakers, and invited guests for their attendance. She joined NLM in August 2016 after serving as a professor in the School of Nursing and College of Engineering, University of Wisconsin-Madison. She is a pioneer in the development of innovative information systems and services, such as ComputerLink, an electronic network designed to improve the lives of home care patients and increase their independence.

Dr. Brennan shared her view of NLM, noting the Library’s 180-year history, and played a video to highlight the history and services of NLM. Key contributions are accelerating research, serving the public and delivering knowledge to the point of need.

“Our contributions fundamentally support discovery. We are one of the 27 institutes of the National Institutes of Health, and we focus on discovery both in terms of how we assist in the biomedical discoveries as well as how we develop new knowledge to understand and make use of our collection,” said Dr. Brennan. NLM is taking on a very special responsibility for the NIH by becoming the hub of data science.

Focusing specifically on the National Center for Biotechnology Information (NCBI), she noted that literature receives about 4 million daily users, molecular and clinical data receive about 300,000 daily users, and specialized datasets receive 15,000 daily users.

Dr. Brennan stated that NLM must provide the platform for accelerating discovery so data continue to be valuable after the initial research work is completed. “We have to store the data in ways that are secure and accessible, and we have to preserve the data in its integrity so it can be used for other studies,” she commented after the showing of a second video.

Dr. Brennan noted that NLM has done an outstanding job over the past 25 years to help society and health care—and particularly health care researchers—understand the value of formal terminologies, of ensuring that the word described as pain in San Francisco means the same thing in New York City. The ability of NLM to attach meaningful standards to data is an important step in being able to drive discovery through data.

Dr. Brennan discussed three kinds of partnerships NLM maintains: (1) biomedical science researchers and investigators who make use of the tools and datasets NLM provides; (2) clinicians who are able to drive better care because NLM delivers knowledge and tools to the point of need; (3) lay people who ensure NLM resources benefit society as a whole. She defined lay people as citizens, patients, friends,

consumers—individuals who are not biomedical science research professionals. Today’s health care system is pushing more responsibility on lay people, so NLM must be available to assist them.

Currently, four panels are engaged in strategic visioning to forecast and create the Library of the 21st century. In the future, many activities and programs will revolve around data, but the Library will not abandon the core mission of managing literature and finding pathways to make the literature and its discoveries understandable to everyone. The Library will expand its extramural research program and will launch an initiative to put the power of data science into the hands of individuals through innovation.

Dr. Brennan reminded EnHIP representatives that health is a highly personal matter. “When we provide our resources, we must remember we are touching a person in a very intimate way, and we need to think of our information not as a pronouncement, but as a dialogue with the individual. Our information must always be actionable,” she said.

In closing, Dr. Brennan urged representatives to join the conversation and submit guest blogs to her blog site. She writes a weekly blog, stays active on Twitter, and posts her e-mail address online to encourage dialogue.

III. Discussion and Q&A with Dr. Patricia Flatley Brennan

Dr. Brennan’s presentation was well received and led to an extended question-and-answer session. Several representatives emphasized the importance of all people having access to materials, and they mentioned several often-overlooked populations, such as people in prison. Dr. Brennan said considerable resources are spent on outreach and customer service. Dr. Robert Valdez, The University of New Mexico, commended NLM on its efforts to convey information in languages other than English.

Dr. Brennan explained that people seek authoritative information because health responsibilities are shifting increasingly to them. “In this day and age when trust in government is fragile, we remain a beacon of important trustable knowledge, and we will stay that way,” she affirmed.

Dr. Cheryl Taylor, Southern University at Baton Rouge, asked Dr. Brennan to share her vision for EnHIP and asked her how representatives can help fulfill future missions. Dr. Brennan made three requests: (1) help NLM use sufficient, comprehensive, and understandable terms to address the health concerns of people in their communities; (2) help develop a workforce that can meet the demands of science and technology; (3) guide NLM in developing effective outreach efforts so it continues to identify and contribute to health conversations in communities.

IV. Introductions

Dr. Patricia Matthews-Juarez, who presided over the meeting attended by representatives of member schools in the District of Columbia, Puerto Rico, and 17 states coast to coast, asked representatives to introduce themselves and brief others about projects they have undertaken in the past year.

V. *All of Us*SM Research Program, Precision Medicine Initiative[®]

Dr. Joni L. Rutter, Director of Scientific Programs, *All of Us* Research Program, described a decade-long program that will accelerate health research and medical breakthroughs, and enable individualized prevention, treatment, and care for everyone. Unlike studies that are focused on a specific disease or population, the *All of Us* Research Program will serve as a national research resource to inform thousands of studies, covering a wide variety of health conditions and various population groups.

The *All of Us* Research Program is a key element of the Precision Medicine Initiative, which launched in fiscal year 2016 when \$130 million was allocated to NIH. Funding is provided in part through the 21st Century Cures Act.

Dr. Rutter stated one million volunteers will supply data about themselves to fill a biomedical database, which will serve as a resource for future research studies and medical advances. The database will reflect the country's broad diversity and include communities that are historically underrepresented in biomedical research. Dr. Rutter labeled it quadruple diversity, referring to diversity of people, health status, geography, and data types. Participants will be true partners and will be involved in research awards, governance, protocol development, and workshops.

In collaboration with federal partners, community partners, provider groups, medical centers, and research institutes, the program team receives guidance on best practices for community engagement and communication. In the months ahead, participants will enroll through health care provider organizations or directly as volunteers.

The *All of Us* Research Program will collect participant questionnaires, electronic health records, baseline physical measurements, and biospecimens (blood and urine samples). Participants will be asked to submit information about their health, personal habits, family health history, health care access, physical activity, environmental exposures, and many other topics. Questions will also be asked about substance abuse, sexually transmitted diseases, and mental health disorders. The program will adhere to the highest standards for privacy and security.

Vanderbilt University, the Broad Institute, and Verily (formerly Google Life Sciences) are developing the architecture for the database so data are brought in, organized, and made useful. Electronic medical records, metabolomics, proteomics, genomics, survey instruments, mHealth data, images, and GIS data will be components fitted into the database. Data sharing will be a priority and will follow a three-tiered approach for access: public, registered researchers, and controlled. Although the information gathered in the *All of Us* Research Program is not a federal dataset and Federal Information Security Management Act (FISMA) does not apply, the program team has chosen to follow the risk-based assessment and adhere to FISMA principles to ensure the information is stored in a very secure environment.

VI. Discussion and Q&A with Dr. Joni L. Rutter

Dr. Sandra Harris-Hooker, Morehouse School of Medicine, facilitated the discussion after Dr. Rutter's presentation and asked about establishing trust and engagement with minority communities. Partners who can advise on communicating with minorities were identified through community engagement workshops and other means. A new funding mechanism known as the Other Transaction Award is designed to reach people who are not typical NIH grantees, but can do community outreach work for the *All of Us* Research Program.

Dr. João Ferreira-Pinto, The University of Texas at El Paso, said members of Latino communities hesitate to give information to the government because of trust issues and fear of U.S. Immigration and Customs Enforcement. Dr. Rueben C. Warren, Tuskegee University and EnHIP Senior Scientific Advisor, asked if EnHIP member universities have been engaged in the program's planning and preliminary groundwork. Dr. Rutter expressed an interest in hearing from EnHIP representatives and encouraged them to e-mail their thoughts about community engagement principles. She explained the significant effort to engage a variety of diverse individuals. The program spans a decade, so any gaps in representation can be addressed as the program progresses. Dr. Michael Thompson, Florida A&M University, and Mr. John C. Scott, Center for

Public Service Communications and NLM Consultant, affirmed the depth of knowledge, experience, and talent held by EnHIP representatives on the topic of community outreach. In noting the benefits from future participation, Dr. Rutter said she looked forward to receiving guidance from EnHIP representatives.

Dr. Doris Withers, Medgar Evers College, City University of New York, asked about the practical applications and immediate benefits. In closing, Dr. Rutter stated a user's point of view: "If I knew that I could change my health outcomes by knowing more about myself, my genes, my environment, and their interaction, then I could prevent a health outcome in the future." She mentioned Lynch syndrome, an inherited condition that increases the risk of colon cancer and other cancers, as an example to illustrate the tangible benefits resulting from the program. An individual with that genetic variant could take action to get screened for colon cancer starting at a young age. "A real goal of the program is to identify ways to prevent a variety of different conditions and help us live longer," said Dr. Rutter.

VII. Open Data Science: Promising Directions and Current Challenges

To begin his presentation, Dr. Audie Atienza, Senior Fellow, ICF International, briefed attendees on terms used to describe open data science. He provided his definition of open data: Publicly available data structured in a way that enables the data to be fully discoverable and usable by end users. He differentiated between open data and research data, indicating research data is recorded factual material commonly accepted in the scientific community as necessary to validate research findings. Also, Dr. Atienza reviewed the definition of open data science, described as research based on greater access to open or public research data and that may or may not involve nonscientists, and the definition of public science, also known as crowd science, or participation of nonscientists and amateurs in scientific research.

Familiar examples of open data science include the Global Positioning System (GPS), available since 2000, Climate Data Online (CDO), available since the 1980s from the National Centers for Environmental Information, and Open NASA, available since the 1950s.

During the administration of President Barack Obama, the U.S. Congress granted federal government agencies broad authority related to the public use of data as a means to spur innovation. In referencing his work with NIH, his previous employer, Dr. Atienza said a data ecosystem was built after the Community Health Data Initiative Forum in 2011. HealthData.gov is a site dedicated to making high-value health data more accessible to entrepreneurs, researchers, and policy makers. Challenge.gov lists prizes and awards to incentivize developers and researchers to develop technology that will reach different groups that could benefit from data. During the White House Open Data Innovation Summit in 2016, strategies for further action and development were initiated.

NIH's announcement in 2015 to allow "preprints" was a game changer for open access, according to Dr. Atienza. Preprints are draft manuscripts that have not completed the peer review process. He referenced this policy shift because it allowed researchers to cite preprints when they sought funding from NIH. Researchers gained access to information more quickly.

Dr. Atienza focused on the Open Science Prize, a collaboration between NIH, Howard Hughes Medical Institute, and Wellcome Trust, a global charitable foundation. Nearly 100 interdisciplinary teams from 45 countries leveraged data and created tools through this initiative. The winner of the grand prize—\$230,000—is a prototype computational tool called Nextstrain that tracks the spread of emerging viruses such as Ebola and Zika. An international team of scientists developed the tool as an open-access system capable of sharing and analyzing viral genomes. The system mines viral genome sequence data that researchers have made publicly available online. Nextstrain then rapidly determines the evolutionary relationship among

all the viruses in its database and displays the results of its analyses on an interactive public website. The competition brought results in six months, a much faster process than the traditional process of grants, contracts, and cooperative agreements.

Dr. Atienza stated that policies are growing in scope for the public release of data for federally funded research. Some regulations, such as those related to the Health Insurance Portability and Accountability Act, are taken into consideration. Resistance to open data science stems from attempts to protect vested interests, careers, and existing policies. Dr. Atienza acknowledged these concerns. In his view, the potential for greater payoff warrants change. “What we are striving for in the big data/open data era is a new understanding with new analysis that leads to something of practical value,” Dr. Atienza said.

VIII. Discussion and Q&A with Dr. Audie Atienza

Dr. Paul B. Tchounwou, Jackson State University, facilitated the discussion after Dr. Atienza’s presentation and asked about the amount of resources needed to support the development of the infrastructure for open data in this particular initiative. Dr. Atienza estimated a five-year grant to fund open data is well under \$1 million a year; however, sustaining the use and the management of the technology is more complex. Public, private, and nonprofit partnerships are needed. Dr. Milton Morris, Benedict College, questioned the use of preprint materials and expressed concern about the validity and reliability of articles that have not gone through a rigorous peer review process. Dr. Atienza called for balance between information that meets all scientific criteria and findings that show potential but need further testing.

IX. Online Resources from the National Library of Medicine

Ms. Laura Bartlett presented an overview of NLM online resources to fortify representatives’ knowledge and equip them for managing data. She is a technical information specialist for the Outreach and Special Populations Branch, Division of Specialized Information Services (SIS), NLM.

Launched in 2015, the Learning Resources Database collects educational materials created by NLM into one location. These materials include videos, tutorials, webinars, and other resources that provide user education on the vast array of NLM products and services, including PubMed®/MEDLINE® and PubMed Central®. The database houses 33 trainings; training materials are available for free. Institutions can use the application program interface (API) to auto-populate these resources to their websites so students and faculty can see the available NLM resources.

A recent NLM training focus is ToxTutor, an introduction tutorial to toxicology. It was updated and enhanced with images and videos in 2016. The tutorial can be accessed on different mobile devices, including mobile phones. The Public Health Information Resources from the National Library of Medicine training course is designed to provide valuable health information resources from NLM and other reliable sources to meet the needs of diverse audiences, public health professionals, and community members. It provides accurate, up-to-date information about emerging concerns such as climate change, new infectious diseases, environmental chemicals, and improvements to community health. The course will be available in July.

The NLM National Training Office offers free, prerecorded trainings and webinars for librarians and others who educate in health information access. Local training is available through regional medical libraries. Skills development topics of interest are emerging health science issues and opportunities, instructional design, and becoming a better trainer.

Ms. Bartlett called special attention to the NLM Georgia Biomedical Informatics Course, a week-long immersive experience hosted at Augusta University, Augusta, Georgia. It provides continuing education

to health care professionals interested in the application of computer technologies to medicine. Thirty participants are selected annually; the application process opens in the fall. All costs for the course including travel, housing, and per diem are supported by NLM.

Ms. Bartlett asked representatives to communicate with her about their topics of interest and their training needs, as well as the training needs of faculty, students, and community members. Dr. Stephanie Bauer, University of Alaska Anchorage, voiced a need for training on public engagement. Dr. Matthews-Juarez spoke of the growing need for librarians with technology credentials. Dr. Doris Withers asked about training to update faculty members about new processes for accessing data.

X. African-American Pharmacogenomics: Where Are We Now?

Dr. Minoli Perera, Associate Professor of Pharmacology, Northwestern University, reviewed the sampling bias in genome-wide association studies, almost all of which have been conducted in populations with European ancestry. She discussed the limitations of using that data to guide drug dosing in minorities and described ongoing research to tailor pharmacogenomics to African-American populations.

As a pharmacologist, Dr. Perera strives to better predict people's response to drugs. Her presentation focused on warfarin, a drug used to prevent blood clotting. Earlier studies found that in European populations, genomically guided dosing of warfarin improves patient outcomes relative to conventional dosing. But in African-American populations, genomically guided dosing using the same genetic markers (SNPs) as are used for European populations is not beneficial, and in fact adversely affects dosing. Dr. Perera stressed the importance of finding SNPs specific to minority populations rather than adapting genetic information from populations of European ancestry to predict outcomes for minorities. She then described her research in identifying SNPs relevant to African Americans, particularly markers for venous thromboembolism and predisposition to bleeding.

Dr. Perera and her collaborators have formed the African American Cardiovascular Pharmacogenomics Consortium (ACCOuNT) to accelerate discovery and translation of pharmacogenomics findings in African Americans. Data will be publicly available for other investigators. The center received funding from the National Institute on Minority Health and Health Disparities (NIMHD). Its innovative discovery project will involve seven institutions located in Washington, D.C., and Chicago, Illinois.

ACCOuNT engages and recruits African-American populations in both cities in coordination with hospitals, patient advocates, community partners, and advertising efforts. The team set up a pilot grant program to help inform African-American groups about pharmacogenomics—what it is, the research that is being done, and the resources available to them.

ACCOuNT's action plan begins with genomics studies, which involve collecting a wide range of data—clinical responses, DNA, transcriptome—from African-American populations; it progresses to outcome studies evaluating specific genomic information in clinical trials; and then it evolves into implementation. The research team will enroll patients who are taking warfarin, clopidogrel, and new oral anticoagulants, and they will look at the participants' drug responses and adverse-event profiles. A second project, running parallel to the first project, will deliver genomic information to the physicians of the participants. The physicians will have access to a Genomic Prescribing System, and they will be able to make medical decisions based on the best data available.

XI. Discussion and Q&A with Dr. Minoli Perera

Dr. Michael Thompson, Florida A&M University, facilitated the discussion after Dr. Perera's presentation and asked about warfarin doses related to African-American patients. Dr. Perera referenced a new trial with findings that show a decreased bleeding risk by using genomically guided therapy, but the trial did not include many African Americans. Dr. Doris Withers commented on study participants self-identifying as African Americans when in actuality they may be 70 percent European descent. Dr. Perera said she maps prospective study participants' genomes and uses an arbitrary cutoff of 70 percent European descent, thereby circumventing the issue of personal self-identification.

XII. Spheres of Ethics in Research

Dr. Rueben C. Warren, Director and Professor of Bioethics, National Center for Bioethics in Research and Health Care, Tuskegee University, and EnHIP Senior Scientific Advisor, began his presentation on science and ethics by saying, "I am convinced you cannot be an unethical person and be an ethical scientist. The two are not compatible."

He reviewed the bioethics and public health ethics violations of the U.S. Public Health Service Syphilis Study at Tuskegee that occurred from 1932 to 1972. Dr. Warren emphasized the U.S. Public Health Service followed no written protocol for the research. The study was characterized by withholding of therapy, cultural insensitivity, deception, and exploitation. In 1997 President Bill Clinton spoke plainly when he issued an apology: "The United States government did something that was wrong—deeply, profoundly, morally wrong." Bioethics violations have occurred in many countries, noted Dr. Warren, who listed the unregulated clinical trials for the drug thalidomide conducted in Canada, Europe, and the United States; the syphilis study conducted in Guatemala in the 1940s; and medical experiments conducted in Nazi Germany during World War II.

To prevent public health ethics violations, Dr. Warren and others have built a framework for public health ethics. He noted that the systematic study of morals, concepts, and theories typically emerges from departments of philosophy or theology. Public health ethics emphasizes the ethical problematic situations related to interests and health of groups, the social justice of the distribution of social resources, and the positive or social rights of individuals. The study of public health ethics requires the practitioner to effectively conceptualize and operate between the tension of individual rights and collective interest.

Health disparities are defined as systematic, potentially avoidable differences in health—or in the major socially determined influences on health—between groups of people who have different relative positions in social hierarchies according to wealth, power, or prestige.

Dr. Warren discussed current research to understand why African Americans do not participate in clinical trials, noting that many believe it is because of the U.S. Public Health Service Syphilis Study. He indicated that is not the reason. He differentiated between asking communities to trust when there is a history of a lack of trust and proving trustworthiness. Institutions such as Howard University, Meharry Medical College, Charles R. Drew University of Medicine and Science, and Morehouse School of Medicine have proved themselves trustworthy, yet they are often overlooked when new projects seek community engagement with African-American populations.

XIII. Discussion and Q&A with Dr. Rueben C. Warren

Dr. Doris Withers, who facilitated the question-and-answer session, asked Dr. Warren about potential threats to safeguards related to privacy and unfair use of personal genetic information. Dr. Warren said interviews on the topic are under way with principal decision-makers and leaders in health, education, and faith communities. Dr. Jannett Lewis-Clark, Tuskegee University, asked Dr. Warren to comment about Henrietta Lack and the HeLa cells. He informed attendees HeLa cells were mass-produced at Tuskegee at no cost. He urged them to build in safeguards when overseeing clinical trials and “raise the red flag” about the possibilities for violations. In consideration of unethical research done in the past, bioethicists at the National Center for Bioethics in Research and Health Care are discussing the severity of consequences to violations whether they be “a slap on the wrist or going to jail.”

Mr. Scott spoke about community engagement in culturally and linguistically appropriate ways. Dr. Warren said trustworthiness takes time to establish. In referencing family members of patients involved in the U.S. Public Health Service Syphilis Study, Dr. Warren said, “I have been in Tuskegee eight years now. The family members are now to the point where they will tell me what they really feel, not what I want to hear.” He urged representatives to build a cadre of knowledgeable and responsible researchers who take measures to establish trustworthiness.

XIV. Farewell Remarks

Ms. Betsy Humphreys, Deputy Director and former Acting Director, NLM, spoke about EnHIP’s contribution to NLM, saying EnHIP has been a huge asset to the Library. Ms. Humphreys, who is retiring in June, began work at NLM in 1973. She recalled the early years of the World Wide Web, a then-unknown information system on the Internet that allows documents to be connected to other documents by hypertext links, enabling the user to search for information by moving from one document to another. The World Wide Web has been central to the development of the Information Age. Ms. Humphreys stated the overriding concern was “What could NLM do to help organize and improve access to high-quality information?” Ms. Humphreys affirmed the Library was successful in providing access, and it will continue to get better as technology evolves. She acknowledged the hard work undertaken at NLM to increase information literacy, and she urged representatives to use NLM tools to evaluate the quality of information.

Ms. Humphreys urged representatives to emphasize the rigor and reproducibility of scientific evidence. She called for value placed on solid research and real data. She referenced a recent conversation in which trust in government, government institutions, and science were discussed. She offered optimism, emphasizing the Library has a global reputation of high quality, and it will continue to flourish and do great work in the future.

Ms. Humphreys said it has been a great pleasure and privilege to attend EnHIP meetings and work with representatives. “You are doing very important work, and you are doing a lot of good, and you are helping us to do better,” she said.

Dr. Ann Barbre, former EnHIP chairman, Xavier University of Louisiana, and other representatives praised Ms. Humphreys’ excellent leadership and contributions to EnHIP. Mention was made of an upcoming retirement party at NLM on June 19. Representatives discussed showing their appreciation of her service in some way.

XV. EnHIP Outreach Awards Presentation

The mission of EnHIP 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. To further this aim, NLM provides funding to member institutions for training and other outreach activities.

Eight institutions were awarded the EnHIP Outreach Awards. Dr. Stephanie Bauer, University of Alaska Anchorage, gave the first of three EnHIP Outreach Awards presentations. Presentations on Day 2 were given by Dr. João Ferreira-Pinto, The University of Texas at El Paso, and Mr. Charles (Chuck) Woepfel and Dr. Wansoo Im, Meharry Medical College. For summaries of all the 2016–2017 projects, see Appendix E.

University of Alaska Anchorage, Anchorage, Alaska

Food Justice in the Arctic: Community Action to Raise Awareness and Mitigate Food Waste in Anchorage Households by Empowering Elementary School Children

Presented by Dr. Stephanie Bauer

Elementary school children in Anchorage, Alaska, became partners with undergraduate students of the University of Alaska Anchorage by using NLM resources to learn about food waste and methods to stem hunger. Dr. Raymond Anthony, EnHIP representative, directed the project. Philosophy students in the class “Food Ethics in the Developing World” were challenged to educate elementary school students about food waste and to teach mitigation strategies.

Students were aware of diverse food cultures and excited to talk about their own food rituals and preferences. They were deeply curious about the food cycle and participated in discussions about global food identities, food waste, and equal access to food. Classroom activities included planting seeds, preparing food, and discussing commercial production of food.

A “Building Healthy Food Communities” symposium was held and opened to the public. It featured three speakers, including a medical reference librarian, who discussed how libraries support equal access to food. MedlinePlus® was promoted as a key resource for learning about diet and nutrition.

Dr. Bauer reported food security and food access are tremendous problems for Alaska because the state imports 95% of its food, transportation and heating costs are high, limitations are placed on traditional food sources such as salmon, and a short growing season limits farming and home gardens.

In response to Mr. John C. Scott’s question about food justice and ethics related to the change of traditional food sources and accessibility, Dr. Bauer said, “In Alaska, there is a lot of panic around the issue and so the cultural issues are interwoven with resource development.” She noted the current political debates about mining and the talk about how people must be resilient with the coming changes. “Some people do not want to talk about resilience because we still need to be talking about issues of justice. Can we be talking about adaptation and mitigation, and at the same time, can we address these enormous problems of justice?” she asked. Representatives discussed concerns often voiced by Native American groups: How do they shift as groups of people, as tribes, to the changing climate when the tapestry of their culture is interconnected with the natural resources that they synchronize into ceremonies and their way of life?

XVI. Report from EnHIP Chairman

Dr. Matthews-Juarez urged representatives to collaborate with each other so the member institutions benefit from combined efforts. In referencing the earlier discussion about bioethics, she called for safeguards to be in place for all national grants. She noted problems with food insecurity and cutbacks in spending for research. As she looked at representatives seated around the room, she said, “I have committed myself this year to mobilizing us to the point where we are at least addressing those issues that affect any of these institutions.”

She acknowledged grants for research are difficult to acquire for many of the member institutions, and she urged strong communication with each other and the National Institute on Minority Health and Health Disparities (NIMHD). A number of EnHIP member institutions have been fortunate to receive grants from NIMHD in recent years. “We need to—as a body—come up with a system of communication so that we can be more collaborative and pool our resources or our strengths,” she said.

“What are the priorities of the EnHIP Partnership?” she asked. “I think if we invest time to do a smart analysis so we are clear about our priorities—or at least the top five priorities—that might help people who want to provide information to us,” she explained.

XVII. Wrap-up and Day 2 Overview

Dr. Matthews-Juarez praised the excellent morning and afternoon presentations. She said the presentations for Wednesday, April 12, would supply a wealth of resources for engagement and research on health disparities. She previewed the projects of the EnHIP Outreach Awards presentations. She closed the discussion at 5 p.m.

Day 2

XVIII. Welcome and Introductions

EnHIP reconvened April 12, 2017, at 8:30 a.m. in the NLM Lindberg Room. Dr. Patricia Matthews-Juarez, EnHIP Chairman, Meharry Medical College, presided. She welcomed attendees and invited them to introduce themselves for the benefit of those who did not attend the first day. Dr. Paul B. Tchounwou, Jackson State University, distributed fliers announcing the 14th International Symposium on Recent Advances in Environmental Health Research. The symposium is slated for September 10–13, 2017, in Jackson, Mississippi. A pre-symposium workshop on NLM Web-based resources for environmental health and biomedical research will be held September 10, 2017.

Dr. Matthews-Juarez asked representatives to reflect on information presented on the previous day and share their ideas about positioning EnHIP for the future. Dr. Robert Valdez, The University of New Mexico, focused on preparing students to work with big data before they enter the workforce. He noted that many of his colleagues push back when asked to make changes to their curricula. He asked, “How do we influence our colleagues about rethinking the curricula and using the resources that are online from NIH to make our curricula more relevant for the direction in which NIH is clearly moving?” Dr. Doris Withers, Medgar Evers College, City University of New York, and Dr. Cheryl Taylor, Southern University at Baton Rouge, discussed sharing information from the presentations with colleagues. Other representatives agreed that faculty members could benefit from receiving information about programs and initiatives presented by

speakers at the meeting. However, it was also noted that the speakers and NLM as a whole could benefit from receiving information about community outreach from representatives. Representatives could play a significant role in improving communications with communities and making information sharing more collaborative.

XIX. PAHO's Health Initiatives Commemorating the United Nations International Decade for People of African Descent (2015–2024)

Mr. John C. Scott, Center for Public Service Communications, introduced Ms. Sandra del Pino, regional advisor on cultural diversity in the Family, Gender, and Life Course Department of the Pan American Health Organization (PAHO). NLM has partnered with PAHO for many years on long-term projects including supporting medical libraries and exchanging health information. Mr. Scott and Ms. del Pino have worked closely on projects related to the health of indigenous people.

Ms. del Pino began her presentation by identifying PAHO as a specialized agency of the Organization of American States (OAS). Thirty-five independent states of the Americas are members of OAS. PAHO is also part of the United Nations system because it is the World Health Organization's (WHO) regional office for the Americas. PAHO resolutions passed in 1993, 1997, 2006, 2010, and 2014 address the exclusion and discrimination of indigenous people, particularly as related to human rights and health needs. She noted the 2014 resolution of universal health coverage is the first priority of PAHO. The 2014–2019 PAHO Strategic Plan recognizes four cross-cutting themes: gender, equity, human rights, and ethnicity. PAHO is the only WHO regional office with ethnicity as a cross-cutting theme.

Her current focus is the International Decade for People of African Descent. Roma people are included in this initiative that examines the social and economic exclusions faced by some groups. A policy document, which will be presented to the Ministries of Health of the Region in September, was developed through a very participatory process involving all countries. It contains five prioritized lines of action:

- Production of evidence – Production and integration management of information and analysis on the health and health determinants of indigenous, Afro-descendant, and Roma peoples.
- Promotion of policy action – Effective policy action addressing ethnicity from the social determinants of health approach.
- Social participation and strategic partnership – Social participation and strategic partnerships with indigenous, Afro-descendant, and Roma peoples, ensuring representativity at all levels.
- Development of ancestral knowledge and traditional and complementary medicine – Intensifying the knowledge dialogue that facilitates the development and strengthening of intercultural health models; promoting a new appreciation of traditional knowledge, practices, and cultural expressions through transmission mechanisms specific to each culture.
- Capacity building at all levels – Capacity building of institutional and community health workers as intercultural facilitators who can create the conditions for knowledge dialogue; professional training provided to indigenous, Afro-descendant, and Roma workers at all education levels.

In giving an example of specific PAHO efforts related to Afro-descendant health, Ms. del Pino described the creation of a universal health plan that aligns with existing health plans. Last year, OAS launched a plan of action for people of African descent and directed PAHO to provide technical support. This inclusive

and cooperative effort required consensus and political support from member states. The very participatory process identified common needs, as well as differences, for the entire region of the Americas. The universal health plan took into account conceptual differences and terminologies from many countries. It follows and reinforces the above-mentioned priority actions. The initiative provided opportunities for building and strengthening strategic alliances with human rights organizations, banking institutions, and United Nations agencies. Some countries that participated in the process, such as Honduras, have requested technical cooperation from PAHO to validate the plan at the country level.

XX. Discussion and Q&A with Ms. Sandra del Pino

Mr. Scott opened the discussion by encouraging participation and collaboration with PAHO. He has worked with PAHO for more than 20 years, and it has been his experience that the United States and Canada tend to think of themselves more as donors than as participants in PAHO activities. The nations advise, donate, and support activities, but it is rare that they engage as partners in activities. He encouraged representatives and their member institutions to engage directly.

Dr. Milton Morris, Benedict College, said students are eager for internship opportunities with organizations like PAHO. If they are students from abroad, they are in the United States on student visas and often run into barriers when looking for internships. Ms. del Pino encouraged him to write to her directly because student internships with PAHO are available. Dr. T. Joan Robinson, Morgan State University, asked how EnHIP representatives can work with Afro-descendants in PAHO in a capacity-building activity. Ms. del Pino was very willing to explore collaboration with Dr. Robinson on an Afro-descendant health project, specifically the development of the Afro Youth Health Plan. Mr. Scott indicated information sharing between PAHO and NLM and establishing a more formal relationship between the two institutions would be very positive steps forward for involvement with projects related to the International Decade for People of African Descent.

In response to two questions about the inclusion of Caribbean countries, Ms. del Pino noted the countries of the Caribbean are included in the policy document presented to the Ministries of Health of the Region. Mentioning the Garifuna people, Mr. Scott said Afro-descendants frequently overlap with indigenous populations in Central America, South America, and Caribbean countries. Mr. Phillip C. (Cody) Marshall, Haskell Indian Nations University, spoke about ancestral knowledge of indigenous people and asked if plans are in place for incorporating ancestral knowledge into the plans of action. He said indigenous communities can be hesitant about releasing ancestral knowledge, referring to it as intellectual property, because of previous exploitation of that information. Ms. del Pino emphasized the importance of incorporating ancestral knowledge into policy and plans of action. She hoped the PAHO Health Services Department will develop a specific strategy for traditional medicine during a June meeting in Nicaragua.

XXI. Update on Minority Health, Health Disparities Research, and Funding Programs

Dr. Michael H. Sayre and Dr. Nancy Breen, both with the National Institute on Minority Health and Health Disparities (NIMHD), presented jointly about scientific programs and measurement tools for data collection and evaluation.

Dr. Sayre, Branch Chief, Division of Scientific Programs, NIMHD, presented the mission of NIMHD: to lead scientific research to improve minority health and eliminate health disparities. To accomplish this, NIMHD plans, reviews, coordinates, and evaluates all minority health and health disparities research and related activities of NIH.

Minority health relates to distinctive health characteristics and attributes of U.S. racial and ethnic minority groups. These groups are often subject to social disadvantage and discrimination. They are underrepresented in the scientific workforce, and they are often not recruited to participate in biomedical research. “So much of what we know about medicine is based on evidence that was collected in populations of predominately European descent, so we do not have a good evidence base for many of these minorities,” said Dr. Sayre.

NIMHD health disparities research includes the following minority health populations: African American or black, Asian (more than 30 countries), American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, and Latino or Hispanic (about 20 countries), as well as people of less privileged socioeconomic status, underserved rural residents, sexual and gender minorities, and others subject to discrimination who have poorer health outcomes.

NIMHD’s Extramural Research Programs framework encompasses various domains of influence that interact across the life course and across generations. The domains are biological, behavioral, physical/built environment, sociocultural, and health care system. The levels of influence are individual, interpersonal, community, and societal.

“Our challenge is to figure out how to integrate information and data from the domains and levels of influence, and to understand how they work together to determine population health and drive health disparities,” Dr. Sayre explained. “We believe that the successful development and application of precision medicine approaches to address health disparities and improve minority health are absolutely going to hinge on greater understanding of the complex interplay between biological, behavioral, social, and environmental risk and protective factors across the life course, and the greater inclusion of health disparity populations in precision medicine research. This is a top priority for NIMHD.”

In 2016, NIMHD Centers for Health Disparities Research focused on precision medicine opened at Stanford University, Northwestern University, Vanderbilt University Medical Center, Medical University of South Carolina, and Yale University. The total budget is \$50 million for the five-year project. Dr. Sayre gave overviews of the research projects of each precision medicine center. The Vanderbilt University Medical Center is of special interest. It focuses on developing new statistical methods to predict risk of disparities, examining the genetic risk factors contributing to health disparities, characterizing the relative contribution of genetic risk factors for asthma and pre-term birth, and implementing person-specific obesity treatment for African-American and Latino men. The NIMHD Center at Vanderbilt is a collaborative initiative of Vanderbilt University Medical Center, Meharry Medical College, and the University of Miami, and it is jointly funded by NIMHD and the National Human Genome Research Institute.

Dr. Sayre discussed the Environmental Health Disparities Research Initiative, a joint effort with the National Institute of Environmental Health Sciences and the U.S. Environmental Protection Agency. The initiative created five Centers of Excellence on Environmental Health Disparities Research, located at the University of Southern California, University of Arizona, The University of New Mexico, Johns Hopkins University, and Harvard University’s T.H. Chan School of Public Health. Their projects cover a wide spectrum: housing, transportation, environmental sustainability, food access, poverty, disease, social stressors, and pollution.

Dr. Sayre introduced his colleague, Dr. Nancy Breen, who provided greater detail about using data elements for projects, such as those undertaken by the NIMHD Centers for Environmental Health Disparities. She is an economist, Office of the Director, NIMHD. Dr. Eliseo J. Perez-Stable, NIMHD Director, is leading the effort to have a consensus toolbox of measures on social determinants of health and to house the toolbox at NLM, an existing central location for data.

To eliminate health disparities, researchers need to know the distribution of the health disparities, understand the causes, identify leverage points for reducing or eliminating the health disparities, and assess interventions. She noted that the causes of health disparities are extremely complex so it can be very challenging to understand and measure them. Dr. Breen emphasized the importance of evaluating interventions systematically. To do so, researchers must track and monitor actions.

Dr. Breen provided the tenants of successful monitoring: widely used and agreed-upon data elements, common outcomes that can be used across disease and conditions over time, and making measurement assumptions explicit. Common data elements are used to standardize the collection of investigational data in order to facilitate comparisons of results across studies and more effectively aggregate information into significant metadata results.

Social determinants of health are measured in the Healthy People 2020 data collection; the determinants are neighborhood/built environment, education, economic stability, health and health care, and social and community context. Common data elements can be shared and compared more efficiently. Application of common data elements is growing because of the increased use of electronic health record data for research, increased use by key organizations such as the U.S. Food and Drug Administration, and increased use in NIH funding initiatives, such as the Precision Medicine Initiative.

XXII. Discussion and Q&A with Dr. Michael H. Sayre and Dr. Nancy Breen

Dr. Cheryl Taylor, Southern University at Baton Rouge, differentiated the meanings of the terms “access to health care” and “access to affordable, quality health care,” indicating efforts should be directed toward achieving the latter. Responding to Dr. Taylor’s question about measuring the impact of the Patient Protection and Affordable Care Act, Dr. Breen indicated studies show big increases in health insurance coverage, especially among African-American and Hispanic populations. Improvements in dental care as a result of the increased coverage are known; however the impact on diseases such as cancer will not be known for a long time.

Dr. Matthews-Juarez referenced the NIMHD Center at Vanderbilt, which is a collaborative initiative of Vanderbilt University Medical Center, Meharry Medical College, and the University of Miami. She said the funding for Meharry Medical College was significantly less than the funding for Vanderbilt University Medical Center. She noted that Historically Black Colleges and Universities (HBCUs), Hispanic-Serving Institutions (HSIs), and Tribal Colleges and Universities (TCUs) have a wealth of experience with minority health and community outreach. Dr. Matthews-Juarez expressed her view that there should be a more definitive way of determining the share of funding for these institutions when requests for applications or project authorization requests focus on minority health or community health. The concern is twofold: receiving funding and developing good, solid scientists who can compete. Small institutions have difficulty competing against large institutions, and they should consider working collectively. Dr. Sayre mentioned NIMHD’s efforts to develop scientists through a variety of fellowship programs and encouraged representatives to prepare their students to submit applications. Other representatives commented on inequitable partnerships and expressed the need to raise questions and collect data about these inequitable partnerships.

XXIII. EnHIP Outreach Awards Presentations

The University of Texas at El Paso, El Paso, Texas

A Survey of Musculoskeletal Pain and Discomfort among Hispanic Construction Workers in the El Paso del Norte Region

Presented by Dr. João Ferreira-Pinto

Note: The presentation described a project that received the EnHIP Outreach Award in a previous year.

The project under the direction of Dr. Gabriel Ibarra-Mejia, The University of Texas at El Paso, focused on the musculoskeletal pain and discomfort among Hispanic construction workers. Texas has about 1 million workers in the construction industry, and the state has the highest number of construction worker deaths in the nation.

The project was designed to explore work-related risks and risk perceptions among Hispanic construction workers. The findings will be used to inform implementation of occupational health safety and wellness intervention programs. One hundred fourteen Hispanic workers at two construction sites provided information for questionnaires and participated in semi-structured interviews. More than three quarters (77%) of the respondents had less than a high school diploma. More than one third (35%) of all workers reported at least one injury that led to loss of worktime. Only 10% of the workers reported an injury they suffered to their supervisors. Almost two thirds (64%) of the workers recalled receiving job-related training; but only 56% recalled that safety was part of the training. Recommendations for interventions included the development of job safety training targeted at specific jobs, especially the safe handling of manual loads and hand tools. Recommendations also emphasized the importance of using appropriate language at the appropriate level of literacy for all training and injury-prevention documents.

Meharry Medical College

Engaging Middle School Students in Citizen Science to Prevent and Control the Spread of the Zika Virus in North Nashville: A Data-Driven Project

Presented by Mr. Charles (Chuck) Woeppel and Dr. Wansoo Im

Mr. Charles (Chuck) Woeppel, Meharry Medical College, began the presentation by stating the program was designed to encourage future biomedical careers among minority students. Students, parents, and faculty affiliated with two Nashville middle schools engaged in research. The project also involved Meharry Medical College students, faculty members from Meharry's Health Disparities Research Center of Excellence, librarians from Nashville public libraries and the Meharry Library, and officials from the Metro Nashville Public Health Department and Metro Nashville Police Department. Their focus was to identify and eradicate mosquito breeding sites to control the spread of the Zika virus in Davidson County.

The project, conducted in collaboration with the National Community Mapping Institute at Meharry, included collecting data and developing an interactive map. Participants were trained to use the Mapper Mobile smartphone app to geocode standing water hazards as potential breeding grounds for mosquitoes. Students learned how to develop data and look at data from a research perspective. Zika virus data drawn from MedlinePlus® informed students as they prepared a presentation during a training session.

To learn communication and community outreach skills, the students developed posters and pamphlets about the Zika virus, mosquito control tactics, and personal protection measures. The students prepared a year-end report to present to the City Council and Board of Education. This aspect of the project reinforced the students' sense of engagement and empowerment. Project leadership was Mr. Woeppel, Dr. Wansoo Im, and Dr. Paul Juarez.

XXIV. Update on the National Oceanic and Atmospheric Administration

Ms. Juli Trtanj, Director, Oceans and Human Health Initiative (OHHI), National Oceanic and Atmospheric Administration (NOAA), began her presentation by reviewing findings from the Climate and Health Assessment produced by the U.S. Global Change Research Program. The program was established by Presidential Initiative in 1989 and mandated by Congress in the Global Change Research Act of 1990. Ms. Trtanj serves as cochair of the Climate Change and Human Health Group.

Scientists predict extreme heat events will occur more frequently and more intensely in the near future. Extreme heat is expected to increase premature deaths by the tens of thousands. Projected heavy rainfall, flooding, and drought are expected to increase health hazards including waterborne disease risk and degraded water quality. The nation's aging water sewage infrastructure has a growing failure rate and is causing the public to lose trust in community leadership. Coastal populations are expected to be more vulnerable to flooding. "Miami floods on a regular basis. They call it 'nuisance flooding.' Well, that is a polite term," commented Ms. Trtanj, explaining that flooding often causes sewage to overflow into the streets.

Changes in the climate are expected to alter geographic and seasonal distribution of existing vectors and related diseases. The range of suitable conditions for the Lyme disease vector has increased dramatically since the 1970s and is expected to expand across much of the eastern half of the United States. Climate change will cause stressors on food security and safety because of new weather patterns, increased use of herbicides and pesticides, and decreased availability of key foods, such as fish.

Ms. Trtanj emphasized climate change's impact on mental health and stress-related disorders. The young and the elderly are seen as most vulnerable; however, middle-aged persons who fill primary caregiver roles will bear a lot of stress because they are the breadwinners.

The cultural heritage of some communities is expected to diminish. As an example, communities on Alaska's barrier islands are moving inland as the encroaching seawater destroys homes and businesses. Hunting and fishing practices—sources of cultural identity—are moving away from the traditions of the past.

The public health community should use the lead time provided by climate-based and ocean-based predictive tools and information. Response can be mounted earlier if communities heed the call to be better prepared for calamities such as disease outbreaks. The NOAA One Health Approach advances the federal agency's science and services to inform health decisions through improved understanding of the linkages between environmental conditions and health outcomes, and through delivery of useful prediction products, data, and tools.

Ms. Trtanj encouraged representatives to use the data collected at NOAA to prevent or mitigate the negative effects of climate change. The NOAA Educational Partnership Program with Minority-Serving Institutions supports human, scientific, and other higher education resource capacity development.

XXV. Closing Remarks

Dr. Matthews-Juarez mentioned intentions to transform EnHIP, and she asked representatives to identify four objectives and develop a work plan. She advised representatives to communicate with their leadership about priority topics, such as precision medicine and data science, and then become actively involved on policy committees to ensure decisions reflect these priorities. She urged meaningful conversation with institution faculty members to promote curriculum development and workforce development in step with the needs of students. Dr. Matthews-Juarez stated, “We need to think globally about implementation of programs that can be used not only in the United States but across the world.”

Dr. Rueben C. Warren, Tuskegee University and EnHIP Senior Scientific Advisor, also commented on the encouraging tone of the meeting, and he said, “Let us get out of the limitations of traditional definitions and scope of science, and let this organization bring us together to do exciting things. Let us stand up and be heard.”

Dr. Matthews-Juarez thanked NLM for hosting the meeting and thanked participants for attending. She adjourned the meeting at 12:30 p.m.

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**NATIONAL LIBRARY OF MEDICINE®
DIVISION OF SPECIALIZED INFORMATION SERVICES
ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP**

Charting a Course for the 21st Century

Environmental Health Information Partnership Strategic Plan

INTRODUCTION

Environmental Health Information Partnership

The Environmental Health Information Partnership (EnHIP) was established by the National Library of Medicine (NLM) in 1991 as the Toxicology Information Outreach Panel. This group was started at a time in which the issue of racial and ethnic health disparities in a myriad of conditions had been elevated into sharp visibility. There was also concern about disparities in potential and real exposure to environmental toxicants and their contribution to disparities in morbidity and mortality. At the same time there was an increase in the complex literature of toxicological science. The Panel then evolved into the Environmental Health Information Outreach Program and subsequently refined into the current state, the Environmental Health Information Partnership. This Partnership reflects a broader focus on the multiple dimensions of environmental health, the environmental health sciences, and health disparities. The objective is to assist in addressing disparities among academic institutions in access to information technology and related pedagogical and research resources.

In this context, it was increasingly recognized that modern instruction, research, and service to communities, students, and professions—the core mission of academic institutions—were nearly impossible without computers and related technologies. Indeed, evidence abounds that the addition of computer science and bioinformatics to the arsenal of environmental health, biomedical, social, behavioral, and clinical research holds enormous promise and continues to stir considerable excitement among researchers, academicians, practitioners, and the entire health services community.

These were among the developments that prompted the NLM to initiate a series of programs and services specifically designed to expand and strengthen its partnership with Minority-Serving Institutions (MSIs) and, in the process, enhance the efforts of these schools to increase the number of racial and ethnic minorities in the environmental health, biomedical research, and health care workforce. The NLM was also interested in ensuring that, through planned outreach efforts, both lay and professional groups were aware of, had ready access to, and utilized the NLMs rapidly expanding collections of medical and health information.

Working together, the NLM and the participating colleges and universities continue to apply themselves to these efforts as the 21st century becomes the digital era, creating a better and a more innovative and collaborative future.

Rationale and Process

The Environmental Health Information Partnership has made substantial progress during the past decade in achieving its initial objectives. A prominent feature of this progress has been information sharing, including regular NLM staff reports on the continuous expansion of the Library databases and programs,

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as well as presentations from other National Institutes of Health (NIH) Institutes and Centers on development in other areas of the NIH, which supports research and discovery that ultimately improves the methods and outcomes of public health services and personal health care. These discussions have added to the substrate of information which academicians need to bring to full fruition the core functions of academic institutions.

The challenge for the Partnership is not only to maintain its role as a progressive component of NLMs outreach efforts, but to advance to even higher levels of productivity consistent with the NLM Long Range Plan (2006–2016) (*Charting a Course for the 21st Century: NLMs Long Range Plan 2006–2016*; http://www.nlm.nih.gov/pubs/plan/lrp06/NLM_LRP2006_WEB.pdf). That plan includes four overall objectives that serve as the reference frame for the Partnership strategic planning process.

The process began with a number of discussions within the Executive Committee, the administrative arm of the Partnership. These discussions, by teleconference as well as face-to-face interactions at the Library on the NIH campus, culminated in a comprehensive review of the NLM Board of Regents-endorsed new 10-year Long Range Plan.

Later, in meetings at the Library, the Partnership organized into four working group, consistent with the NLM plan's four goals. Each group was charged with sorting from the 66-page Library plan challenges, and strategies for the partnership—all within the context of the overarching mission of the Library.

The outcome was a report of each working group's deliberations. As with any broad-ranging discussion among multidisciplinary academicians with differing perspectives, numerous important and relevant topics were discussed, a number of which were beyond the boundaries of NLMs statutory responsibilities. The Executive Committee attempted to capture the key themes of all of the working group reports. The results of that effort are reflected in the plan that follows.

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Florida A&M University, Tallahassee, Florida
Chairman, National Library of Medicine Environmental Health Information Partnership

VISION

EnHIP will be a strong, stable, and effective partner of NLM as the Library becomes even more central to scientific discovery and treatment and prevention of disease. Through this partnership, NLMs programs and services, adapted to 21st century health and health sciences developments, will further strengthen the capacity of MSIs to perform three important and fundamental functions within the public health and health care system. These are: 1) educate and train health professionals; 2) conduct basic and applied research in disciplines pertinent to biomedicine, health services, health care, and health disparities; and 3) engage in community, public, and professional services.

MISSION

The mission of the Environmental Health Information Partnership 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.

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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. Department of Education, <http://www.ed.gov/about/offices/list/ope/index.html>).

STRATEGIC GOALS

Goal I. Seamless, Uninterrupted Access to Expanding Collections of Biomedical Data, Medical Knowledge and Health Information

Objectives of the Partnership for Achieving Goal 1

- Assess the current capacity of MSIs to access NLMs databases and related Library resources that can enhance efforts of these colleges and universities to carry out their fundamental mission.
- Use the above-cited assessment to develop a program that will address the deficiencies revealed in the survey.
- Expand and intensify efforts to ensure that MSI faculty and students are thoroughly knowledgeable of detailed aspects of NLMs collections of health and biomedical information.
- Provide technical assistance and related resources to aid MSIs in increasing knowledge and use of NLM programs and services by lay and professional groups within their surrounding communities.
- Initiate appropriate action to include selected MSI libraries in the National Network of Libraries of Medicine (NN/LM).
- Initiate the necessary administrative and logistical procedures to ensure that future NLM exhibits are available for display in MSI communities.
- Convene a seminar, first at NLM and then at MSIs, on the “hows and whys” of disaster management information.
- Determine the extent of instruction in disaster management at MSIs and potential interest in disaster management information research consistent with the research agenda that may emerge from the NLM Disaster Information Management Research Center (DIMRC).

Goal 2. Trusted Information Services that Promote Health Literacy and the Reduction of Health Disparities

Objectives of the Partnership for Achieving Goal 2

- Structure a program to provide opportunities for interested students from MSIs to gain “field experience,” i.e., internships) in the operational aspects of NLM, including the management of the expansive databases and related activities.
- Initiate discussions with consumer advocacy groups in MSI communities to plan an intensive consumer awareness campaign designed to increase the number of consumers who are aware of and use NLMs free high quality consumer information resources.
- Develop specific recommendations for increasing the number of underrepresented minorities in the library sciences workforce.

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- Convene a symposium on research advances in environmental health, climate change effects, and the animal-human connection as it relates to disease, designed to enhance the understanding of librarians of the multiple dimensions of the confederations of disciplines that comprise the environmental health sciences and the implications of these advances for both NLM programs and services and for those of local library services.
- Emphasize and promote the importance of MSI community high school teachers' and students' understanding of environmental health, climate change, and the animal-human connection as it relates to disease, as well as knowledge and use of NLM environmental health databases.

Goal 3. Integrated Biomedical, Clinical, and Public Health Information Systems that Promote Scientific Discovery and Speed the Translation of Research into Practice

Objectives of the Partnership for Achieving Goal 3

- Determine the extent of electronic medical records use by physicians, hospitals, and clinics in MSI communities.
- Use data from the preceding objective as basis for a seminar/discussion on the development of electronic health records including presentations of case studies in which health records were essential source of data.
- Increase MSI faculty members' awareness of the value of electronic health records in environmental health and related research.
- Enhance MSI faculty involvement in translation of public health research findings and knowledge to evidence-based practice.
- Expand Partnership understanding of the NLM online resources and their relevance to the mission of MSIs.
- Increase MSI students' and communities' knowledge of "hows and whys" of the NLM online resources and their relevance to consumer and academic services.
- Attract new students to the field of environmental health research, including the study of climate change effects, comparative medicine, and vector-borne diseases.
- Play a leadership role in encouraging community engagement in research activities of MSIs.
- Increase research productivity and, in the process, increase contributions of MSI faculty members to professional journals.

Goal 4. A Strong and Diverse Workforce for Biomedical Informatics Research, Systems Development and Innovative Service Delivery

Objectives of the Partnership for Achieving Goal 4

- Increase NLM/Partnership visibility in MSI communities.
- Increase Partnership knowledge of NLMs programs and services designed to shape biomedical informatics education and training.
- Play a leadership role in initiating discussions of career opportunities in biomedical informatics and library science, including the promotion of interest in these careers.
- Ensure a prominent role for the NLM/Partnership in "career day" or similar programs at MSIs.

Attract new MSI students to health sciences librarianship through NLMs postgraduate Associate Fellowship Program.

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ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP MEETING

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BIOGRAPHIES

Audie Atienza, PhD, joined ICF International in January 2016 as a senior fellow in biomedical informatics. He supports a number of high-priority projects for ICF including providing subject matter expertise in biomedical informatics to the National Library of Medicine® (NLM). Previously Dr. Atienza was a senior advisor to the Associate Director for Data Science (ADDS) at the National Institutes of Health (NIH). He led the Open Science Prize initiative for the ADDS. He was senior advisor to the chief technology officer at the U.S. Department of Health and Human Services (HHS), Office of the Secretary, where he led health technology initiatives in collaboration with the White House, the Office of the U.S. Surgeon General, and the Office of the National Coordinator for Health Information Technology. He also served as a behavioral scientist in the Division of Cancer Control and Population Sciences at the National Cancer Institute. He holds a doctorate in clinical psychology.

Laura Bartlett, MLS, is a technical information specialist for the Outreach and Special Populations Branch, Division of Specialized Information Services (SIS), NLM. She works primarily with the information resource development for specific population groups, project/program management, and training. She earned a master of library science degree from the University of Maryland, College Park.

Stephanie Bauer, PhD, is an associate professor of philosophy at the University of Alaska Anchorage (UAA) and the chair of the Department of Philosophy. She is also the interim director of UAA's Ethics Center, which sponsors lectures and research in applied ethics and offers ethics workshops for professional development. She is a faculty fellow and cofounder of UAA's Dialogues for Public Life. Her work with this group grew from a 15-month training at the Kettering Foundation on facilitating public deliberation on shared public problems. Dr. Bauer teaches and does research on issues in biomedical ethics and disaster ethics. One of her current research projects is on the nature of resilience in the rapidly changing Arctic. She holds a bachelor's degree from Pacific Lutheran University and a master's degree and doctorate from Washington University in St. Louis, Missouri.

Nancy Breen, PhD, is an economist working in the Office of the Director, National Institute on Minority Health and Health Disparities (NIMHD). She coleads the Science of Health Disparities Visioning Process as it relates to methods and measurement science in health disparities research. Prior to joining NIMHD, Dr. Breen spent more than 20 years at the National Cancer Institute, where she designed and managed research programs, developed and disseminated data analysis tools, identified ways to more effectively use survey data to support health disparities research, and disseminated written and oral findings to a range of audiences. She has published more than 100 peer-reviewed articles.

Patricia Flatley Brennan, RN, PhD, MS, is the Director of the National Library of Medicine. She came to NLM in August 2016 from the University of Wisconsin-Madison, where she was a professor in the School of Nursing and College of Engineering. She is a pioneer in the development of innovative information systems and services, such as ComputerLink, an electronic network designed to improve the lives of home care patients and increase their independence. She directed HeartCare, a Web-based information service that helps home-dwelling cardiac patients recover faster and with fewer symptoms, and Project

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Health Design, an initiative designed to stimulate the next generation of personal health records.

A past president of the American Medical Informatics Association, Dr. Brennan was elected to the Institute of Medicine in 2001. She is a fellow of the American Academy of Nursing, the American College of Medical Informatics, and the New York Academy of Medicine.

Sandra del Pino, JD, is the regional advisor on cultural diversity in the Family, Gender, and Life Course Department of the Pan American Health Organization (PAHO) of the World Health Organization (WHO). Ms. del Pino focuses on providing technical cooperation to member states with regard to the health of the different ethnic/racial groups living in the Americas. She holds a law degree from the University of Seville and a translations degree from the University of Geneva. She also holds a master's degree in intercultural mediation. She has extensive experience in the field of human rights. Before joining PAHO in 2010, she worked for WHO in the Western Pacific Regional Office in Manila, the Philippines, and the United Nations Office of the High Commissioner for Human Rights in Geneva, Switzerland.

João Ferreira-Pinto, PhD, is an associate research professor and director for research in the College of Health Science, The University of Texas at El Paso. He also serves as director for the Center for Interdisciplinary Health Research and Evaluation. Prior to his current appointment, Dr. Ferreira-Pinto was an assistant professor of behavioral sciences at The University of Texas Health Science Center-Houston, School of Public Health, in El Paso.

Dr. Ferreira-Pinto's research interests center on HIV/AIDS/STD and drug abuse prevention and treatment, community and organizational development, environmental justice, and qualitative evaluation methodologies. Most of his work is based in fostering collaboration between academics and community organizations to improve community-based participatory research and the quality of life among underserved populations.

Betsy L. Humphreys, MLS, has served as the Deputy Director of the National Library of Medicine since 2005. She shares responsibility with the Director for overall program development, program evaluation, policy formulation, direction, and coordination of all Library activities. Ms. Humphreys also coordinates extensive activities related to health data standards, serving as U.S. member and founding chair of the General Assembly of the International Health Terminology Standards Development Organization. She contributes to the development of NIH and HHS policy on a range of matters, including health information technology, public access to research results, and clinical trial registration and results reporting. Ms. Humphreys is an elected member of the National Academy of Medicine (previously the Institute of Medicine) of the National Academy of Sciences, a fellow of the American College of Medical Informatics, and a fellow of the Medical Library Association (MLA). She is the recipient of a number of awards, including the Morris F. Collen Award of Excellence from the American College of Medical Informatics, considered the highest honor in the field of medical informatics; the Marcia C. Noyes Award, which is MLA's highest honor; and the first Cornerstone Award conferred by the Association of Academic Health Sciences Libraries. She received a bachelor of arts degree from Smith College and a master of library science degree from the University of Maryland, College Park.

Wansoo Im, PhD, is the Director of the National Community Mapping Institute, a researcher in the Health Disparities Research Center of Excellence (HDRCOE), and an associate professor of family and community medicine at Meharry Medical College. He specializes in developing decision support systems using a public participatory approach to the geographic information system (GIS). He joined the fac-

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ulty in 2016 to lead the National Community Mapping Institute and curate public health exposome data with complete metadata. He has pioneered the use of interactive, Web- and mobile-based GIS to support community-based participation and research on social and environmental issues. Dr. Im holds bachelor's, master's, and doctoral degrees in urban planning.

Patricia Matthews-Juarez, PhD, is Meharry Medical College's Vice President of Faculty Affairs and Development, and she serves as a professor in the Department of Family and Community Medicine. She works on environmental health disparities and research training at Meharry's Health Disparities Research Center of Excellence.

From April 2013 through August 2015, she was cofounding director of the Research Center on Health Disparities, Equity, and the Exposome (RCHDEE) and a professor in the Department of Preventive Medicine at the University of Tennessee Health Science Center, Memphis. Prior to her work with RCHDEE, Dr. Matthews-Juarez was a professor in Meharry's Department of Pediatrics and the founding Dean and Associate Vice President of the Office of Faculty Affairs and Development. She holds a bachelor's degree from Fisk University, a master's degree from New York University, and a doctorate from Brandeis University.

Minoli Perera, PharmD, PhD, is an associate professor of pharmacology at Northwestern University. In addition to earning dual doctoral degrees, she trained as a fellow in clinical pharmacology and pharmacogenomics. During her two-year clinical fellowship, Dr. Perera trained within a human genetics laboratory studying novel variants related to pharmacokinetic differences in CYP3A4 in African Americans. This training highlighted the complexities of genetic studies in admixed populations, such as African Americans, and integrated her clinical and basic science backgrounds. As she started her faculty position, she became interested in clinical translation of pharmacogenetic findings, but soon realized that African Americans are often excluded from these studies.

Dr. Perera has received funding from the National Heart, Lung, and Blood Institute and American Heart Association to investigate novel genetic variants associated with warfarin dose response. She is the principal investigator for one of five Transdisciplinary Collaborative Centers funded through the NIMHD.

Joni L. Rutter, PhD, is the Director of Scientific Programs with the All of UsSM Research Program of the Precision Medicine Initiative® at NIH. Prior to joining the All of Us Research Program, she was the division director of neuroscience and behavior at the National Institute on Drug Abuse (NIDA). In this role, she led integrated research on basic and clinical neuroscience, brain and behavioral development, genetics, epigenetics, computational neuroscience, bioinformatics, and drug discovery. She coordinated the NIDA Genetics Consortium and biospecimen repository.

Dr. Rutter is internationally recognized for her work in basic and clinical research in human genetics and in the study of genetic and environmental risk factors focusing on the fields of cancer and addiction. She received a doctorate from Dartmouth Medical School and completed a fellowship at the National Cancer Institute. Her primary scientific objective is to integrate genetic principles with environmental influences to inform the understanding of how individual and societal influences impact health and disease.

Michael H. Sayre, PhD, is a branch chief in NIMHD's Division of Scientific Programs. Dr. Sayre oversees a broad extramural research grant portfolio focused on minority health and health disparities, including the Centers of Excellence program and the Research Centers in Minority Institutions Program. Prior to joining NIMHD, he was deputy director of the Division of Research Infrastructure in the National

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Center for Research Resources. He began his NIH career at the Center for Scientific Review, where he managed reviews of grant and fellowship applications focused on molecular genetics and cell biology.

Before joining NIH, he was a faculty member in the biochemistry department at Johns Hopkins University. His research on fundamental mechanisms of gene regulation, supported by the National Science Foundation, the American Cancer Society, and NIH, has yielded 30 peer-reviewed journal articles and numerous invited lectures and presentations at scientific conferences.

John C. Scott, MS, is the Founder and Director of the Center for Public Service Communications. Its mission is to provide guidance and expertise to individuals, communities, and public sector organizations in the specialized field of applying telecommunications and information technologies to reduce health disparities, improve health services to underserved and disenfranchised individuals and communities, and improve the collection and sharing of scientific, technical, and community knowledge to reduce human vulnerability to natural hazards.

From 2001 to 2005, Mr. Scott established and was executive director of the National Congress of American Indians (NCAI) President's Task Force on Health Information and Technology. Mr. Scott is Tlingit and a member of the Tlingit and Haida Indian Tribes of Alaska.

Mr. Scott has been a consultant to NLM and the Environmental Health Information Partnership (EnHIP) for more than 20 years. He received a bachelor's degree from the American University and a master's degree from the Kogod School of Business at the American University.

Juli M. Trtanj, MES, is the Director of the Oceans and Human Health Initiative (OHHI), National Oceanic and Atmospheric Administration (NOAA). The main goals of OHHI are to lead the development and delivery of health early warning systems to reduce ocean-related health risk and to enhance the health benefits from ocean-derived food and natural products. In addition to her work with OHHI, Ms. Trtanj has worked to design and direct the Climate Variability and Human Health Program. This program is focused on developing capacity to use climate information to reduce health risks in Africa, Asia, and Latin America. She also developed and managed a joint climate and health research program with the National Science Foundation, the Environmental Protection Agency, and EPRI (formerly the Electric Power Research Institute).

Ms. Trtanj is responsible for developing and coordinating NOAA's health portfolio with other federal, state, local, and international agencies, and academic and private sector partners. Her research interests are in the development and application of ecologically based early warning systems for public health and common resource management. Ms. Trtanj earned a master's degree from Yale School of Forestry and Environmental Studies.

Rueben C. Warren, DDS, DrPH, MDiv, is the Director of the National Center for Bioethics in Research and Health Care at Tuskegee University. He serves as a professor at Tuskegee University and as an adjunct professor of public health, medicine, and ethics and as director of the Institute for Faith-Health Leadership at the Interdenominational Theological Center in Atlanta, Georgia. From 2005 to 2007, he served part-time as the director of infrastructure development, NIMHD. From 1988 to 1997, Dr. Warren served as associate director for minority health at the Centers for Disease Control and Prevention (CDC). Prior to joining CDC, Dr. Warren served as dean and associate professor of the School of Dentistry at Meharry Medical College.

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Dr. Warren earned an undergraduate degree from San Francisco State University, a DDS degree from Meharry Medical College, and a master's degree and doctorate from the Harvard School of Public Health. In June 1990, Dr. Warren received the Distinguished Harvard Alumni Award. Dr. Warren also completed a master of divinity degree from the Interdenominational Theological Center, and he is an ordained minister.

His extensive public health experience at community, state, local, national, and international levels ranges from leading clinical and research work at the Lagos University Teaching Hospital in Lagos, Nigeria, to heading the Public Health Dentistry Program at the Mississippi State Department of Health. Dr. Warren has contributed to the scientific literature in public health, oral health, ethics, and health services research. His professional associations include the Health Braintrust of the Congressional Black Caucus of the United States, National Dental Association, American Board of Dental Public Health, American Public Health Association United Nations Children's Fund, and World Health Organization. From 1996 to 1997, he served as chairperson of the Caucus on Public Health and Faith Communities, an affiliate of the American Public Health Association.

Charles (Chuck) Woeppel, MBA, a health care executive, has a record of demonstrated success driving strategic, financial, and operational management of academic and small-to-large private practice physician groups, as well as proven achievement in managing multiple hospital organizations. He has strong operational knowledge in all aspects of health care management, service delivery, and contracting. Following Hurricane Katrina, he wrote a grant and business plan for new hospital construction and received \$35 million in funding through Gulf Opportunity Zone Bond Funds to support a private equity venture to help with construction and equipment purchase in New Orleans, Louisiana.

Mr. Woeppel has deep involvement with middle and high school education. Under his leadership, Meharry Medical College created a focused biomedical and technology interest program in association with the Metro Nashville School System. He served as project manager for the Zika Virus and Technology Program, a community mapping and science project coordinated by Meharry with support from the EnHIP Outreach Award.

Mr. Woeppel earned a master of business administration degree in health care administration from Xavier University, Cincinnati.

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ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP DIRECTORY OF CURRENT REPRESENTATIVES 2016–2017

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APPENDIX E

Environmental Health Information Partnership Meeting—April 11-12, 2017

ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP ENHIP PROJECTS 2016–2017

Benedict College, Columbia, South Carolina

Improving Minority-Serving Institutions' Knowledge of National Library of Medicine Resources Through Competitive Student Presentations

This project will extend the previously funded program, which engaged teams or individuals in topics relevant to the priorities of the Environmental Health Information Partnership and the National Library of Medicine® (NLM). Students will use NLM databases and resources to conduct research, and then they will make presentations about their findings. The students are members of Benedict College's Student Environmental Health Association.

Charles R. Drew University of Medicine and Science, Los Angeles, California

Understanding Our Environment to Improve Health Outcomes

The project director and an assistant will hold a series of training sessions for students from the King/Drew Medical Magnet High School. With a focus on environmental health information, the training sessions will show students how to access and use NLM resources, such as the Household Products Database, TOXMAP®, Haz-Map®, and Tox Town®. By completing the learning exercises, they will be better prepared to improve the environmental health of their communities and their own health. Upon completion of the training sessions, the students will attend meetings at community organizations and demonstrate the utilization of NLM resources, thereby training the members of these organizations. Activities will culminate with an Environmental Health Symposium at Charles R. Drew University of Medicine and Science. This event will feature presentations by experts on environmental health, environmental justice, household toxins, and personal health. The students will provide demonstrations on using NLM resources.

Colorado Mountain College, Glenwood Springs, Colorado

Providing Information and Training to Immigrant Families in Environmental Health Impacts and Community Health Careers

The EnHIP Outreach Award will cover tuition and books for 15 Hispanic immigrant community members enrolled in a home health aide course that will lead to their certification as personal care attendants. As part of the training, the participants will learn how to use NLM digital resources for consumers. They will be able to use this knowledge to promote healthier lifestyle choices, and they will be better informed about environmental health issues and health disparities. Participants will be identified by three local community programs: Eagle River Youth Coalition's (ERYC) InteGreat! Program, Youth Power 465, and Early Head Start providers. An ERYC member who is a recent graduate of Colorado Mountain College's Sustainability Studies Program will provide two enhancement classes. One class will focus on food security and nutrition; its curriculum was developed in 2014 through an EnHIP project. A second class will concentrate on leadership training to address environmental and nutritional health within neighborhoods.

Medgar Evers College, City University of New York, Brooklyn, New York

Providing Access to and Use of Environmental Health Information to Community Stakeholders to Reduce Environmental Health Disparities

The EnHIP Outreach Award will be used to develop instructional materials and present workshops that utilize online NLM materials to enrich the knowledge of students and faculty on the topics of human variation, health, and the environment, as related to genomics.

APPENDIX E

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Meharry Medical College, Nashville, Tennessee

Engaging Middle School Students in Citizen Science to Prevent and Control the Spread of the Zika Virus in North Nashville: A Data-Driven Project

About 108 middle school students, plus their parents and teachers, will join forces with Meharry Medical College students and others to identify and eradicate mosquito breeding sites to control the spread of the Zika virus in Davidson County. The project, conducted in collaboration with the National Community Mapping Institute, will include collecting data and developing an interactive map. They will engage officials from the Metro Public Health Department, librarians from Nashville public libraries and the Meharry Library, and faculty members from Meharry's Health Disparities Research Center of Excellence.

Morehouse School of Medicine, Atlanta, Georgia

Project Health and Environment Information Resources (Project HEIR)

Project Health and Environment Information Resources, an initiative about accessing and using NLM environmental health resources, will feature 10 training sessions. Professional staff at the M. Delmar Edwards, M.D. Library, Morehouse School of Medicine, will lead the trainings. Participants will include faculty, public health students, medical science students, and public librarians from a 10-county region. The public library system serves a population estimated to be 10,214,860.

University of Alaska Anchorage, Anchorage, Alaska

Food Justice in the Arctic: Community Action to Raise Awareness and Mitigate Food Waste in Anchorage Households by Empowering Elementary School Children

Senior-level students who are enrolled in the Ethics, Community, and Society class led by EnHIP representative Dr. Raymond Anthony will partner with five elementary school classes in the Anchorage School District. They will gain a better understanding of food systems sustainability and local food security by using mapping techniques. The project will combine ethics, science, and library resources to address food waste at the consumer level. It will expose students to sources of health and social justice information and will advance their knowledge and expertise related to food insecurity.

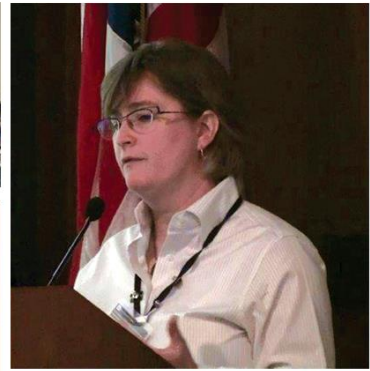
The University of Texas at El Paso, El Paso, Texas

Workshop for Applying GIS Community-Based Mapping for the Identification of Environmental Health Disparities in the El Paso del Norte Region

Students enrolled in the Master of Public Health program will design and conduct a workshop based on the NLM course Community Health Maps. They will use GIS tools and techniques to engage in health data collection for the development of community health maps of the Paso del Norte Region. Students will have the opportunity to enhance their skills for data collection and collaboration with government and nongovernment institutions.



**National Library of Medicine Environmental Health Information Partnership Meeting
History of Medicine Reading Room
April 11-12, 2017**



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