



Environmental Health Information Partnership

Translating data and information to
accelerate biomedical discovery and to
improve health equity:

A Strategic Platform for Biomedical Discovery and Data-Powered Health

Proceedings
April 3-4, 2019

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

**ENVIRONMENTAL HEALTH
INFORMATION PARTNERSHIP**

PROCEEDINGS

BETHESDA, MARYLAND
APRIL 3–4, 2019

***TRANSLATING DATA AND INFORMATION TO ACCELERATE BIOMEDICAL DISCOVERY
AND TO IMPROVE HEALTH EQUITY: A STRATEGIC PLATFORM FOR BIOMEDICAL
DISCOVERY AND DATA-POWERED HEALTH***

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 Oak Ridge Associated Universities (ORAU).

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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: Translating Data and Information to Accelerate Biomedical Discovery and to Improve Health Equity: A Strategic Platform for Biomedical Discovery and Data-Powered Health

**Conference Room B, 2S-04
Mezzanine, Bldg. 38
APRIL 3–4, 2019
Patricia Matthews-Juarez, PhD, Presiding**

AGENDA

WEDNESDAY, APRIL 3, 2019

- 8:00 a.m. – 8:30 a.m. Registration
- 8:30 a.m. – 9:00 a.m. **Meeting Opening and Welcome**
Patricia Matthews-Juarez, PhD, Chairman, EnHIP
Senior Vice President for Faculty Affairs and Development
Professor, Department of Family and Community Medicine
Meharry Medical College
- Rueben C. Warren, DDS, DrPH, MDiv
Senior Scientific Advisor
Professor & Director, National Center for Bioethics in
Research and Health Care
Tuskegee University
- 9:00 a.m. – 9:30 a.m. **Report from NLM Director**
Patricia Flatley Brennan, RN, PhD
Director, National Library of Medicine
- 9:30 a.m. – 9:45 a.m. **Discussion and Q&A**
Facilitated by Patricia Matthews-Juarez, PhD
- 9:45 a.m. – 10:15 a.m. **All of Us Research Program**
Amanda Wilson, MS
National Network Coordinating Office, Library Operations
National Library of Medicine
- Dara Richardson-Heron, MD
National Institutes of Health

- 10:15 a.m. – 10:30 a.m. **Discussion and Q&A**
Facilitated by Sandra Harris-Hooker, PhD
Morehouse School of Medicine
- 10:30 a.m. – 10:40 a.m. BREAK
- 10:40 a.m. – 11:00 a.m. **Overview – NIH Tribal Health Research Office/Support of Data Science and Research**
David Wilson, PhD
Director, Tribal Health Research Office
Office of the Director, National Institutes of Health
- 11:00 a.m. – 11:15 a.m. **Discussion and Q&A**
Facilitated by Stephanie Bauer, PhD
University of Alaska, Anchorage
- 11:15 a.m. – 11:45 a.m. **Developing a Diverse Workforce in Data Science**
Charlene Le Fauve, PhD
Office of the Director, Senior Advisor
Scientific Workforce Diversity, National Institutes of Health
- 11:45 a.m. – 12:00 p.m. **Discussion and Q&A**
Facilitated by Dolores Caffey-Fleming, MS, MPH
Charles R. Drew University of Medicine and Science
- 12:00 p.m. – 1:15 p.m. LUNCH
- 1:15 p.m. – 1:45 p.m. **EnHIP Group Picture**
Chia Chi Charlie Chang
Photographer, National Institutes of Health
Lister Hill Lobby
- 1:45 p.m. – 3:30 p.m. **Strategic Planning Session Starts**
- Each group will have a facilitator and a scribe to report back to the group on strategies that will be incorporated in the implementation plan for EnHIP
 - Format of the breakout groups
 - Discussion and consensus
 - Overview of resources
 - Solutions, approaches, and strategies
 - Collaborations and partnerships
 - Recommendation for implementation
 - Timeline
 - Responsible person at the institutional level

Breakout Groups

GOAL 1: Accelerate discovery and advance health by providing the tools for data-driven research

- 1.1 Connect the resources of a digital research enterprise*
- 1.2 Advance research and development in biomedical informatics and data science*
- 1.3 Foster open science policies and practices*
- 1.4 Create a sustainable institutional, physical, and computational infrastructure*

GOAL 2: Reach more people in more ways through enhanced dissemination and engagement pathways

- 2.1 Know NLM users and engage with persistence*
- 2.2 Foster distinctiveness of NLM as a reliable, trustable source of health information and biomedical data*
- 2.3 Support research in biomedical and health information access methods and information dissemination strategies*
- 2.4 Enhance information delivery*

GOAL 3: Build a workforce for data-driven research and health

- 3.1 Expand and enhance research training for biomedical informatics and data science*
- 3.2 Assure data science and open science proficiency*
- 3.3 Increase workforce diversity*
- 3.4 Engage the next generation and promote data literacy*

3:30 p.m. – 3:40 p.m.

BREAK

3:40 p.m. – 4:40 p.m.

Continued Discussions on Strategic Plan

4:40 p.m. – 4:50 p.m.

Wrap-up and Day 2 Overview
Patricia Matthews-Juarez, PhD

**NATIONAL LIBRARY OF MEDICINE
ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP
Conference Room B, 2S-04
Mezzanine, Bldg. 38**

AGENDA

THURSDAY, APRIL 4, 2019

- 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
Senior Vice President for Faculty Affairs and Development
Professor, Department of Family and Community Medicine
Meharry Medical College
- Rueben C. Warren, DDS, DrPH, MDiv
 Senior Scientific Advisor
 Professor & Director, National Center for Bioethics in
 Research and Health Care
 Tuskegee University
- 9:00 a.m. – 11:00 a.m. **New EnHIP Strategic Plan**
Patricia Matthews-Juarez, PhD
- 11:00 a.m. – 11:15 a.m. BREAK
- 11:15 a.m. – 11:30 a.m. **Honoraria & Travel Reimbursement**
LaFrancis Gibson, MPH, CHES
Health Education Specialist Section Manager
Oak Ridge Associated Universities
- 11:30 a.m. **Closing Remarks**
Patricia Matthews-Juarez, PhD
Chairman, EnHIP

**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 3–4, 2019**

The Environmental Health Information Partnership (EnHIP) convened its annual meeting on April 3, 2019, at 8:32 a.m. and continued the morning of April 4, 2019, in Building 38 of the National Library of Medicine® (NLM) in Bethesda, Maryland. The theme of the meeting was “Translating data and information to accelerate biomedical discovery and to improve health equity: A strategic platform for biomedical discovery and data-powered health.” EnHIP Chair, Dr. Patricia Matthews-Juarez, professor, Department of Family and Community Medicine and senior vice president of the Office of Faculty Affairs and Development, Meharry Medical College presided at the meeting.

The annual EnHIP meeting adjourned at 11:34 a.m. on April 4, 2019.

Presiding Chair

Dr. Patricia Matthews-Juarez, Meharry Medical College

Senior Scientific Advisor

Dr. Rueben C. Warren, Tuskegee University

ATTENDEES

Representatives from Participating Institutions

Ms. Dolores 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. Betty Damask Bembenek, Colorado Mountain College

Dr. João Ferreira-Pinto, The University of Texas at El Paso

Dr. Sandra Harris-Hooker, Morehouse School of Medicine

Ms. Judith Mazique, Texas Southern University

Dr. Milton A. Morris, Benedict College

Dr. Daniel Sarpong, Xavier University of Louisiana

Dr. Kim Sydnor, Morgan State University

Dr. Paul B. Tchounwou, Jackson State University

Dr. Robert Valdez, University of New Mexico

Dr. Doris Withers, Medgar Evers College, CUNY

Alternate Representatives

Dr. Stephanie Bauer, University of Alaska Anchorage

Ms. Ann Krejci, Oglala Lakota College

Ms. Maletta Payne, Southern University at Baton Rouge

Dr. Constance Smith-Hendricks, Tuskegee University

Dr. Syreeta Tilghman, Florida A&M University

Speakers

Dr. Patricia F. Brennan, Director, NLM
Dr. Charlene Le Fauve, NIH
Dr. Dara Richardson-Heron, NIH
Ms. Amanda Wilson, NLM
Dr. David Wilson, NIH

Guests

Ms. Karen Hamick, Colorado Mountain College

NLM Staff

Ms. Dianne Babski, Division of Library Operations, NLM
Ms. Joyce Backus, Division of Library Operations, NLM
Ms. Florence Chang, Division of Specialized Information Services, NLM
Ms. Cynthia Gaines, Division of Specialized Information Services, NLM
Ms. Janice E. Kelly, Division of Specialized Information Services, NLM
Ms. Muriel Midon, Division of Library Operations, NLM

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Ms. Kelli Bursey, Oak Ridge Associated Universities
Ms. Wanda Gamble, Oak Ridge Associated Universities
Ms. LaFrancis Gibson, Oak Ridge Associated Universities
Dr. Ashley Golden, Oak Ridge Associated Universities
Dr. Denise Parker, Oak Ridge Associated Universities

Day 1

I. Meeting Opening and Welcome

Dr. Patricia Matthews-Juarez, EnHIP chair, called the meeting to order at 8:32 a.m. on April 3, 2019. She welcomed and thanked EnHIP members for attending and contributing to the work and vision of NLM and asked them to think about two important matters: (1) what each member brings to NLM through EnHIP, and (2) how each member can mentor junior faculty to become more involved in the EnHIP partnership as the focus shifts toward a world of data-driven activities and work. She also requested that the attendees keep in mind the three goals of the NLM Strategic Plan 2017–2027 as they work toward developing the EnHIP strategic plan. She invited each member to introduce themselves and share one personal “fun fact” with the group, starting with EnHIP senior scientific advisor, Dr. Rueben C. Warren.

Dr. Warren, professor and director of the National Center for Bioethics in Research and Health Care at Tuskegee University, commended the EnHIP representatives for their longstanding commitment to EnHIP and offered his thoughts about the path forward. “Information is data and data is information, but sometimes people get them confused. Our charge is to make data real so people can understand and use it.” He noted that data collection, translation, and dissemination flow together, and if the translation is misinterpreted, utilization of the data can become inappropriate. He also reminded the EnHIP group that “sometimes we don’t understand, and we have to accept that.” Finally, Dr. Warren urged the EnHIP representatives to think now about who will succeed them and how to prepare their successors to “receive the baton” and carry on.

The other attendees then introduced themselves, and Dr. Matthews-Juarez concluded the introductions with a recollection from an earlier meeting where a Haskell Indian presenter showed the image of a moon and talked about the environment. She explained how a lifetime of environmental exposures and related health effects define the public health exposome, which she and other EnHIP members have been examining as environmental health research questions. As emerging scientists enter the field of environmental health, “ideas are generated, ideas are taken, and ideas are implemented. And they become realities not only for our schools but for the nation.”

Dr. Matthews-Juarez again thanked everyone and introduced the first speaker, Dr. Brennan.

II. Report from NLM Director

Dr. Patricia Flatley Brennan, director of NLM, thanked EnHIP members for attending the meeting and commented that the EnHIP/NLM partnership is critical in helping NLM to meet its responsibilities to society as well as understand how to best meet those responsibilities. She prefaced her slide presentation with comments about a recent publication documenting racial-ethnic disparities in air pollution exposures and said the EnHIP/NLM partnership is important in stimulating research to prevent such disparities in the future.

Dr. Brennan’s presentation began with a brief summary of the capabilities and services of NLM. The library serves as a national archive and distribution center for health information and for health data around the world and strives to make data findable, accessible, interoperable, and reusable

(also known as the FAIR principles). In addition to providing literature and data resources, the NLM conducts research and demonstration projects in health and biomedical sciences, and increasingly in environmental sciences. Dr. Brennan explained how library patrons can register with MyNCBI and create a profile that will allow NLM to regularly send literature likely to be of interest to the patron. She also described the NLM “canned searches,” which are structured searches designed to facilitate quick access to information on a specific topic.

The remainder of Dr. Brennan’s presentation elaborated on NLM efforts to implement the three goals of the Strategic Plan 2017–2027. Beginning with Goal 1: Accelerate discovery and advance health by providing the tools for data-driven research, she discussed the NLM-funded work of Davidson,¹ who is trying to reengineer precision medicine therapeutics through N-of-1 trials. This clinical trial method uses statistical techniques to leverage the study of just one patient, using data-driven criteria, to optimize individualized treatment. Another project known as HealthMap, which was initially supported by an NLM grant, provides a global, geographic picture of health to help identify where health risks, such as disease outbreaks, are appearing in the world. Dr. Brennan’s last example of NLM-funded research to address Goal 1 was the work of Hadley et al.,² which describes a method of digital crowd-curation, guided by the FAIR principles, “to translate big data into precision medicine.”

The second NLM goal—to reach more people in more ways through enhanced dissemination and engagement pathways—focuses specifically on using NLM resources to reduce health disparities. Dr. Brennan briefly described research by Morgan³ on the use of Bayesian statistics to combine personal medical information with population statistics, thereby improving treatment decisions. She explained that advances such as this can be disseminated effectively through the National Network of Libraries of Medicine® (NNLM) to a wide range of researchers and practitioners. Another important project to enhance information dissemination and community engagement is the *All of Us*SM program, in which NNLM is again playing a key role by providing a source of quality, trustable information in every community. The last project presented by Dr. Brennan in support of Goal 2 was research by Zeng-Treitler et al.⁴ to develop pictographs for improving health communication in, for example, emergency rooms and situations where the patient might not speak

¹ Davidson KW. Re-engineering precision therapeutics through N-of-1 trials. Bethesda, MD: National Institutes of Health, Research Portfolio Online Reporting Tools, Project Information. 2017 [cited 2019 Jun 3]. Available from: https://projectreporter.nih.gov/project_info_description.cfm?projectnumber=5R01LM012836-02

² Hadley DD. Crowd-assisted deep learning (CrADLe) digital curation to translate big data into precision medicine. Bethesda, MD: National Institutes of Health, Research Portfolio Online Reporting Tools, Project Information. 2018 [cited 2019 Jun 3]. Available from: https://projectreporter.nih.gov/project_info_description.cfm?projectnumber=5U01LM012675-02

³ Morgan DJ. Incorporating Bayesian reasoning into physician testing and treatment decisions. Bethesda, MD: National Institutes of Health, Research Portfolio Online Reporting Tools, Project Information. 2018 [cited 2019 Jun 3]. Available from: https://projectreporter.nih.gov/project_info_description.cfm?icde=0&aid=9350055

⁴ Zeng-Treitler Q, Kim H, and Nakamura C. Assessment of pictographs developed through a participatory design process using an online survey tool. *J Med Internet Res* [Internet]. 2009 Feb 24 [cited 2019 June 3]. <https://www.jmir.org/2009/1/e5/>

English. Zeng-Treitler’s unique approach employed a participatory design process using an online survey tool to refine the pictographs and ensure they accurately conveyed the intended message. Building a workforce for data-driven research and health is the third strategic goal, and Dr. Brennan discussed a broad range of initiatives aimed at achieving the objective, beginning with a data science readiness survey of all NLM staff, including herself. She asserted that “the NLM leadership views the data science readiness of our staff as one of the assets that we must understand, cultivate, and develop to make sure we’re ready for the future. . . We recognize that we need to train our researchers and our library science staff and our outreach staff in understanding what data science can do and what can be done for individuals.” NLM provides training at 16 universities to prepare pre- and post-doctoral students for careers in biomedical informatics and data sciences and also offers numerous research grant supplements and fellowships to encourage librarians and researchers to pursue careers related to biomedical data science. In particular, NLM promotes diversity in the workforce by specifically supporting students and investigators from underrepresented groups and offering financial supplements to facilitate re-entry to active biomedical and behavioral research careers after an interruption such as extended family leave or a stint in industry.

Other projects funded by NLM span multiple strategic goals, and Dr. Brennan reviewed ongoing research along these lines. NLM is developing tools to train NNLM librarians in data science and to help the librarians reach people in their communities. She mentioned a project to establish “personal health libraries” with resources to help individuals make sense of health-related information, such as their genetic code. Another project is looking at augmented reality or virtual reality headsets to help people interact and engage with health information. For example, the headsets could provide nutritional information about a food item that the headset-wearer is considering for breakfast. NLM is funding principal investigator Dr. Rita Kukafka to lead a project called Conexion, which involves working with a Hispanic community to incorporate culturally important considerations and contextual data into health information. For example, if mothers typically make the health decisions for families in the community, that should be taken into consideration when disseminating information. If a particular diet or product is recommended, tools can direct people to a store in their community that carry those products. Dr. Brennan presented several more examples of outreach projects dealing with subjects as varied as food advertising, mapping environmental health issues in a community, and computational linguistics studies to facilitate doctor-patient telephone interactions. The idea behind all of these projects is to “reach people where they are,” to bring health knowledge into people’s everyday lives in a way that is understandable and useful.

Dr. Brennan finished her presentation with mention of a continued NLM commitment to HIV/AIDS and the information needs around that topic. She thanked the EnHIP representatives for their attention and offered to answer any questions.

III. Discussion and Q&A with Dr. Brennan

Dr. Warren began the discussion by asking whether NLM has any projects with public school systems rather than just individual schools and universities. Dr. Brennan answered that NLM recognizes the importance of reaching public school systems, particularly in the effort to build the workforce, but the mandate for the National Institutes of Health (NIH) targets outreach at the

college and post-college level. Kindergarten through high school is primarily the domain of the National Science Foundation (NSF). Nonetheless, Dr. Brennan said NLM will be partnering more with NSF in the future through various interventions at the high school level that would introduce data-science concepts in advanced placement classes that are already offered at some high schools. She also added that NLM does have outreach to individual schools and is moving to a more systematic approach so that schools who might be interested are aware of opportunities to engage with NLM for additional resources.

Dr. João Ferreira-Pinto, The University of Texas at El Paso, asked for guidance on training campus personnel in data science skills because he has encountered indifference among his peers at the university. Dr. Brennan passed the question to Ms. Dianne Babski, Division of Library Operations, NLM, who responded that NLM has determined the data science prerequisites for different positions (data support staff, data scientist, etc.), and has defined ten different competencies to meet those prerequisites. NLM has developed training courses to satisfy those competencies, but they are just for internal use at this time. Dr. Brennan interjected to say she could provide more information later this year or early 2020 once NLM has more experience with the training process. With regard to lack of interest among staff, Dr. Brennan commented that some staff say they have “always done data science” and do not need training. She responds by telling them three facts: (1) the amount of data available now is vastly greater than in previous decades; (2) the sheer volume of data requires different analytical techniques than used previously; and (3) data is not just for scientists now and is employed across almost all disciplines. Data science must pervade the entire campus. Ms. Babski and Dr. Brennan noted that NNLM has a large portfolio of data science courses on its Web site, from basic to advanced, some of which include a training segment.⁵ These are available to anyone, and some are free.

Dr. Doris Withers, Medgar Evers College, CUNY, asked Dr. Brennan to elaborate on the concept of people submitting genomic data for analysis and wanted to know what NLM would be providing to researchers. Dr. Brennan replied that the next speaker, Dr. Dara Richardson-Heron of NIH, would be talking about the *All of Us* research program and would answer that question in detail. Dr. Brennan explained the program briefly and emphasized the goal of collecting data from a wide range of individuals, especially those from populations typically underrepresented in health research. She also addressed concerns about data privacy and discussed several efforts to protect privacy.

Dr. Milton A. Morris, Benedict College, asked Dr. Brennan for ideas about how to ensure that students taking electronic courses can have unimpeded access to data at NLM. Dr. Brennan responded that NLM has many public data sets that are readily available, and she offered to give EnHIP representatives the link to a Web page that lists NLM data sets.⁶ She did note that only

⁵ National Network of Libraries of Medicine. Training. Overview [Internet]. Bethesda, MD: National Institutes of Health. [cited 2019 Jun 3]. Available from: <https://nmlm.gov/data/training>

⁶ The NCBI data resources and NIH data sharing repositories are respectively located at:

- National Center for Biotechnology Information (NCBI). All Resources [Internet]. Bethesda, MD: U.S. Library of Medicine, National Institutes of Health. [cited 2019 Jun 3]. Available from: <https://www.ncbi.nlm.nih.gov/guide/all/>

parts of the NLM database are authorized for unrestricted use because of personal privacy considerations. Summary genomic data, for example, can be viewed to see how common a certain mutation is.

Dr. Brennan again thanked EnHIP members for engaging in conversation with NLM and helping NLM to reach communities much more effectively than it could otherwise do alone. Dr. Matthews-Juarez followed with a brief introduction of the next speaker, Dr. Richardson-Heron.

IV. *All of Us* Research Program

Dr. Richardson-Heron, NIH, is the chief engagement officer for the *All of Us* research program. She began her talk by thanking EnHIP for their work with NLM, which indirectly led to her involvement with Ms. Amanda Wilson of NLM. She stated that the mission of the *All of Us* program is “to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us, not just a select few.” The plan is to enroll at least a million volunteers and assemble one of the most diverse cohorts in the nation to participate in a long-term study. Data related to health, lifestyle, and environment will be gathered and analyzed to see how these factors interrelate. The researchers hope to make the data widely available for study and identify steps individuals can take to stay healthy longer. The role of the NLM includes curating the data and making it accessible and usable for anyone who wishes to study it.

Dr. Richardson-Heron encouraged EnHIP members to sign up and learn more about the *All of Us* database. She explained the three tiers of data access: public, registered, and controlled. The greater the risk to participants’ privacy, the more stringent the access requirements. The data are not yet available but should be available later this year through the homepage for the *All of Us* research hub, which Dr. Richardson-Heron previewed to EnHIP members.

The rest of Dr. Richardson-Heron’s presentation dealt with the transformational approach incorporated in all aspects of the *All of Us* program. The participants who provide their personal data are involved as partners, with a voice in what data are collected, how it is collected, what research is conducted, and how data and information will be responsibly returned to participants in a way that is valuable to them. The effort to assemble a diverse cohort transcends the usual attempts at diversity by ensuring “quadruple diversity,” which refers to a wide variety of people, geographic locations, participant health status, and types of data collected. Perhaps most importantly, the *All of Us* program is designed to create value for participants and engender trust on a number of levels: participant privacy is rigorously guarded; people of all types are included so everyone can benefit, including populations typically underrepresented in health research; trusted community members are being employed as intermediaries to ensure participants understand and benefit from the research program; and enrollment options offer potential participants a choice of how to become part of *All of Us*.

Dr. Richardson-Heron concluded her talk with a report on progress to date in recruiting participants and partners, and she extended a personal invitation to EnHIP members to join the program as a

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- Trans-NIH BioMedical Informatics Coordinating Committee (BMIC). NIH Data Sharing Repositories [Internet]. Bethesda, MD: U.S. Library of Medicine, National Institutes of Health. [cited 2019 Jun 3]. Available from: https://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html

participant, a researcher, or whatever capacity feels appropriate. She provided the *All of Us* Web site address for signing up, and then invited Ms. Wilson to speak.

Ms. Wilson’s presentation focused on how NNLM, the main arm of NLM outreach, is supporting the *All of Us* program. The partnership has three goals: (1) provide training for libraries, (2) provide funding for innovative projects, and (3) provide community connections. The first goal covers a broad spectrum of training, including confidence-building of public library staff in providing health information; learning to use the *All of Us* online platform; and learning how to engage communities through library outreach. Ms. Wilson explained that the structure of NNLM, with eight regions across the country, coupled with *All of Us* engagement counselors strategically placed in each of the regions, facilitates implementation of the partnership goals across the entire United States and its territories. NNLM has also added two new centers of excellence to address training/education and community engagement.

As part of the first goal, NNLM is helping public library staff to become certified in consumer health information. This enables the staff to help patrons quickly find the health information they need. The *All of Us* online platform provides internal training on digital health literacy, and other trainings assist researchers who wish to access *All of Us* data. The second goal encompasses a number of ongoing projects that dovetail with the community connection goal. For example, NNLM libraries host a traveling *All of Us* bus exhibit promoting the program with hands-on activities that teach visitors about precision medicine and how they can participate in *All of Us*. Pop-up libraries in laundromats are funded through the Wash and Learn program, which provides health information as well as *All of Us* enrollment information. The Book Bikes program is another innovative NNLM project that employs bike couriers to carry books to populations who cannot or do not visit the library. All of these projects bring *All of Us* to the communities, meeting people where they are.

The rest of Ms. Wilson’s presentation enumerated the *All of Us* community partnerships that NNLM has been involved with. The Public Library Association recently endorsed the *All of Us* research program and the NNLM/*All of Us* partnership work. Summer library programs now include a health component tied to the summer theme. Several health-related citizen science projects and citizen science game days are on the calendar this year to get people involved in data science and possibly interested in participating in *All of Us*. Ms. Wilson expressed interest in aligning with the Historically Black Colleges and Universities (HBCU) Library Alliance and invited EnHIP representatives to share other ideas for reaching historically underrepresented groups.

V. Discussion and Q&A with Dr. Richardson-Heron and Ms. Wilson

Dr. Sandra Harris-Hooker, Morehouse School of Medicine, facilitated the question-and-answer session and began by asking the presenters to share their thoughts on how the *All of Us* program can enlist the NLM to retain project participants and how EnHIP members can assist. Dr. Richardson-Heron replied that the *All of Us* program is hoping their community partners, including the NLM, will be the “key drivers of retention” by helping *All of Us* participants to better understand the information they receive from the program. Efforts to improve health literacy are vitally important. She further requested that partners continue to ask *All of Us* participants what

they need from the program to stay involved and engaged, because the answer will be different for different people.

Dr. Robert Valdez, University of New Mexico, first thanked Ms. Wilson for remembering the U.S. territories.⁷ He commented that federal programs frequently forget about the territories and treat those populations as “second class citizens,” and he was encouraged that the *All of Us* program will include them. Dr. Valdez voiced concern, however, about the lack of access to high-speed Internet in many communities, including the small rural and frontier communities he works with in New Mexico. Digital literacy is not possible until Internet connections are brought to those communities. “If there’s any Internet connection in those communities, it’s at the library, so you’re partnering with the right folks,” he said. “You’ve just got to get them the right equipment. Otherwise, we’re still on dial-up, if you remember what that is!”

Dr. Robert L. Copeland, Jr., Howard University, asked whether *All of Us* includes children as participants and pointed out the opportunity to make observations over a lifetime. Dr. Richardson-Heron responded that the program systems and infrastructure are being designed initially for adults. Participants must be at least 18 years of age and cannot be a prisoner. These constraints are in part due to legal considerations, but the plan is to eventually include children.

Dr. Kim Sydnor, Morgan State University, expressed an uneasiness about data privacy, particularly over the long term. Governments and leadership change, so “what guarantees can be given now for tomorrow?” She was also wary of commercialization stemming from *All of Us* data, and specifically, who the beneficiaries of that commercialization would be. Dr. Sydnor brought up the possibility that minority-serving institutions would have the freedom to access *All of Us* data but not the capacity to do so. Dr. Richardson-Heron acknowledged that “privacy is probably the biggest risk to participation in our program,” but the *All of Us* team is doing everything possible to put protections in place, even going so far as to engage hackers to see if they can breach the security system. Regarding the capacity of minority-serving institutions to benefit from the data, Dr. Richardson-Heron commented that one of their partners, the National Minority Quality Forum, had made the same point, and discussions are underway to address the issue.

Dr. Daniel Sarpong, Xavier University of Louisiana, followed up on Dr. Harris-Hooker’s earlier question regarding long-term retention of participants. His point, however, was not just how to retain participants but also how to ensure that the results coming out of the *All of Us* program “hit the emotional chord and result in behavior modification.” Without that follow-through, he argued, “we’ll be back where we are today.” Dr. Richardson-Heron reiterated her hope that community partners would help with retention by presenting information to communities in ways that resonate with those communities. She emphasized the importance of sensitivity to literacy levels and culture and acknowledged the challenge of keeping participants involved and engaged.

⁷ There are five major U.S. territories (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, U.S. Virgin Islands) and nine minor outlying island territories (eight in the Pacific Ocean and one in the Caribbean Sea). A U.S. territory is a partially self-governing piece of land under the authority of the U.S. government.

- U.S. Citizenship and Immigration Services. U.S. Territories [Internet]. Washington DC: U.S. Citizenship and Immigration Services. 2019 [cited 2019 Jun 3]. Available from: <https://www.uscis.gov/tools/glossary/us-territories>

A final comment on the presentations came from Dr. Constance Smith-Hendricks, Tuskegee University, who said she was still uncomfortable recommending the *All of Us* program because of the uncertainties around data security, accessibility, and many of the other issues discussed previously. She did credit Dr. Richardson-Heron and Ms. Wilson with increasing her level of comfort, but she could not at that point recommend the program to her peers. She also took the opportunity to object to the removal of the human science training from the NIH Web site. Dr. Richardson-Heron responded that she respected and understood the skepticism but hoped the *All of Us* program would soon demonstrate its value with some important health finding. She pointed out that “if we’re not all part of the research, we may not all benefit from it.” She closed by suggesting that those who are still uncomfortable with *All of Us* watch over time and consider participating if they feel more at ease with the program later.

Before continuing with the EnHIP meeting agenda, Dr. Matthews-Juarez added her thoughts about the *All of Us* program, building on some of the earlier comments. She identified three key points: (1) choosing the right person to advocate for *All of Us* becomes very important at the level of the community; (2) long-term retention of *All of Us* participants is critical, and consideration should be given to funding more of the organizations downstream who are expected to maintain participants’ interest in the program over time; and (3) EnHIP involvement in *All of Us* is very important because of the number of member schools that are in minority communities and serve minority populations. She added that the NNLM regional librarians should be contacting and working closely with the institutions represented by EnHIP to leverage the strategies these institutions already have in place to reach minorities. Dr. Matthews-Juarez once again thanked the speakers and, after a break, resumed the meeting.

VI. Overview of NIH Tribal Health Research Office and Their Support of Data Science and Research

Dr. David Wilson, NIH, began his presentation with an overview of the Tribal Health Research Office (THRO), of which he is director. The office was established in 2015 and is grounded in the recognition of Indian Tribes as sovereign nations. The federal trust responsibility, which arose out of treaties and federal land acquisitions from Indian Tribes, obligates the U.S. government to honor federal programs and services that benefit American Indians and Alaska Natives. The U.S. government recognizes 573 Indian Tribes, each being a unique entity with its own culture, language, and government structure.

THRO is located in the Office of the Director of NIH, which is part of the U.S. Department of Health and Human Services (HHS). Dr. Wilson’s office works with 27 other institutes and centers within NIH to coordinate all Tribal health research activities across NIH, and also interacts with numerous other agencies in HHS, particularly the Indian Health Services (IHS) and the Substance Abuse and Mental Health Services Administration (SAMHSA). To emphasize this multifaceted relationship, THRO has created an image of a dreamcatcher with THRO in the middle and its many partners surrounding THRO. He mentioned that last year, THRO, IHS, and SAMHSA consulted with Tribal nations to address the opiate epidemic in Indian country, marking the first time two agency directors engaged in official, formal consultation with Tribal leaders.

Two committees play a major role in assisting THRO with its work: the Trans-NIH Tribal Health Research Coordinating Committee (THRCC) and the NIH Tribal Advisory Committee. THRCC comprises representatives from each institute or center within NIH and coordinates programs and activities across NIH to eliminate redundancy and identify the most effective programs. The NIH Tribal Advisory Committee consists of representatives nominated by Tribal leaders from all of the Indian Health Service Areas in the United States,⁸ which is intended to elicit a cross-section of issues and ideas that are important to Tribal communities across the nation. Dr. Wilson stated that Indian Tribes are very interested in biomedical research but believe the effort must be a partnership between the communities and researchers. Concerns such as data sharing and management, intellectual property rights, and collaboration throughout the entire process (not just during data collection) are of paramount importance.

With input from both committees, THRO has completed its first American Indian/Alaska Native (AI/AN) research portfolio analysis and will very shortly issue its strategic plan for Tribal health research. The latter lays out four goals: (1) enhance communication and coordination; (2) build research capacity; (3) expand research; and (4) enhance cultural competency and community engagement. Goal 4 overlays the other three, and the strategic plan as a whole will help NIH unify their approach to engaging with Tribal communities.

The remainder of Dr. Wilson’s presentation elaborated on what THRO is doing in the areas of community engagement, professional development, and scientific engagement. The overriding message was that THRO must listen to Tribal concerns and change the paradigm for implementing programs. He spoke about challenges within the Navajo Nation and about establishing a dialogue with the Hayasupai who were the subjects of unethical research practices in the 1990s. He held up the health services program for Alaska Natives as an exemplary paradigm. Developing the next generation of professionals will require new infrastructure within Tribal communities to provide opportunities for biomedical science graduates, and Dr. Wilson is encouraging Tribal communities to work with THRO toward that end. Finally, Dr. Wilson invited researchers interested in working with Tribal communities to look for funding opportunities using a Web-based AI/AN grant finder associated with the Indian Health Service map, and to consider partnering with the Tribal Epidemiology Centers, which have big data sets but inadequate analytical capacity.

VII. Discussion and Q&A with Dr. Wilson

Dr. Smith-Hendricks noticed that the Creek Indian Tribe in Alabama was not on Mr. Wilson’s map even though the Tribe exerts considerable political influence in the state. Dr. Wilson⁹ clarified that the map showed only land-based Tribes, and there are hundreds of Tribes without a defined Tribal

⁸ The Indian Health Service is divided into 12 physical areas of the United States: Alaska, Albuquerque, Bemidji, Billings, California, Great Plains, Nashville, Navajo, Oklahoma, Phoenix, Portland, and Tucson. Each of these areas has a unique group of tribes that they work with on a day-to-day basis.

- Indian Health Service. Locations [Internet]. Rockville, MD: Indian Health Service, U.S. Department of Health and Human Services. [cited 2019 Jun 3]. Available from: <https://www.ihs.gov/locations/>

⁹ Part of the question-and-answer session with Dr. Wilson was delayed until the afternoon because of scheduling conflicts. For purposes of continuity, however, the two sessions are recorded as one morning session.

land. Furthermore, only federally recognized Tribes appear on the map, which excludes 66 state-recognized Tribes that are trying to get federal recognition.

Dr. Warren asked whether THRO is engaging the Tribes that are not federally recognized, and Dr. Wilson responded that Tribes must be federally recognized to establish the government-to-government relationship required by the Tribal Technical Advisory Group of the Centers for Medicare and Medicaid Services. However, unrecognized Tribes can still participate in workshops and training and have been invited to do so.

Dr. Valdez congratulated Dr. Wilson on his considerable accomplishments since becoming the director of THRO and asked whether THRO is involved with the *All of Us* program. Dr. Wilson replied that THRO is currently helping the *All of Us* program to engage in formal consultation with the Tribes regarding participation and the numerous concerns that must be addressed before they agree to participate. Dr. Warren, Dr. Stephanie Bauer (University of Alaska Anchorage), Dr. Matthews-Juarez, and other EnHIP representatives followed up with additional questions about data security and confidentiality, who will control data access, who will pay for treatment if health conditions are discovered, and the overall role of THRO in community engagement for *All of Us*. Dr. Wilson explained that at this point, THRO is trying to help *All of Us* become more transparent in their communication efforts with Tribal communities. He acknowledged the obstacles to *All of Us* participation and commented that “the best we can do is inform communities of what the inherent risks are and let them make the decision to participate or not.”

Dr. Sydnor asked how the dreamcatcher image was received by other institutes because it does not fit the conventional style for an office emblem. Dr. Wilson said the initial response was surprise, but the graphic messaging has been effective, as THRO has demonstrated its ability to connect with the Tribal communities and establish enduring relationships that respect the traditional cultures and practices of Tribal peoples.

Dr. Bauer prompted discussion about institutional review boards (IRB) with a request for advice on how IRBs can support researchers through the compliance process. She has observed that many researchers fear IRBs and seem to avoid research on Alaska Native populations because of compliance issues. Dr. Wilson suggested that IRBs provide a concise statement about what their IRB does and how they can support and help the researcher. IRBs should emphasize that their function is to provide safeguards to protect the community, not to set up roadblocks to research. Ms. Ann Krejci, Oglala Lakota College, asked if THRO will help groups set up IRBs. Dr. Wilson responded that THRO is currently collaborating with the University of Washington to define the critical elements of a successful, sustainable, and effective IRB and expects to issue guidance on that early next year. Dr. Ferreira-Pinto added that it is sometimes possible to tap into IRBs at a local university if an organization does not have the resources to form its own.

Dr. Morris asked for Dr. Wilson’s thoughts about a recent situation where an entity who had potentially polluted a minority community contracted with three HBCUs to conduct research related to the pollution event. The research revealed possible health effects, and the entity not only informed the community but offered financial compensation. The entity did address the concerns of the community but, in return, asked the researchers not to publish the research because of negative public relations concerns. Dr. Wilson recounted a similar incident that affected Tribal

communities. In that case, the National Institute of Environmental Health Sciences funded a local investigation to define the extent of the damage. Dr. Wilson suggested that something similar could be done in this case.

The final question for Dr. Wilson came from Dr. Matthews-Juarez, who wanted to know if THRO is working with Tribal chiefs and governors to develop an approval process for research and whether THRO considers the schedules for Tribal council meetings when issuing funding opportunity announcements (FOA). Dr. Wilson referred to an agreement the Navajo Nation is drafting to put appropriate protections in place so that ethical research can be conducted, and they can benefit from it in the future. The hope is that other Tribes can use this as a model to draft their own research participation agreements. Regarding coordination of FOAs with council meetings, Dr. Wilson indicated that THRO is instead trying to change policy at the Office of Extramural Research to require researchers to build an extra year into their schedules for IRB review.

VIII. Developing a Diverse Workforce in Data Science

Dr. Charlene Le Fauve, NIH, delivered a presentation on behalf of Dr. Hannah Valantine, Chief Officer for Scientific Workforce Diversity at NIH. She began with a review of her own personal career trajectory and noted the challenges and unique experiences during her life that prepared her for her current position. She noted that diversity of experience as well as diversity in a range of sociocultural factors can improve creativity, innovation, independent problem-solving, appreciation for changing demographics, and workforce resilience, among other benefits.

Scientific workforce diversity faces four key challenges. First, the science behind achieving workforce diversity is relatively new, and the evidence for what works and what does not work is still being gathered. Second, psychological and social factors play into bias and can discourage diversity. Third, institutional barriers and other factors can interfere with recruitment and retention of a diverse workforce. The fourth challenge builds upon success in overcoming the first three challenges and addresses sustainability, or the ability to maintain a nationwide diverse workforce over time.

To take on these challenges, NIH assembled the Diversity Program Consortium and launched the BUILD program. This program grew out of recognition that NIH needs to do more in terms of (1) bringing infrastructure to relatively underserved institutions, (2) providing research experiences for underrepresented groups, and (3) developing a systematic way to measure the effectiveness of these and other activities intended to increase diversity. The Diversity Program Consortium, which comprises ten institutions that NIH funded and coordinated with a data center, is testing various interventions to increase diversity, including “living and learning” communities and mentoring programs. Efforts are underway to better understand bias and stereotyping, which have been demonstrated in scientific studies to influence hiring decisions.

Interventions at the individual level are necessary but not sufficient to achieve workforce diversity. Dr. Valantine decided about a year ago to target interventions at the institutional level, starting with the NIH. This has entailed a systematic review of hiring and promotion procedures and policies, as well as the development of tools for enhancing recruitment and retention of minorities. Search committees now undergo implicit-bias training, and a distinguished scholar program has

been set up, which is a community of 15 principal investigators within the extramural research program at NIH who are committed to diversity and inclusion. Dr. Valentine's office has created a toolkit to help NIH conduct proactive outreach to diversify the talent pool under consideration for positions, and to foster mentoring relationships, among other supportive measures. Over time, the effectiveness of these measures will be assessed to see if they actually improve diversity. Once NIH has identified the most effective means of achieving diversity of its own workforce, they can share that information with others.

Dr. Le Fauve concluded her presentation with a reference to the NLM research grant supplements, which Dr. Brennan mentioned earlier. These financial supplements encourage librarians and researchers, particularly those from underrepresented groups, to pursue careers in biomedical data science. The NIH Scientific Workforce Diversity Office has assembled a task force to look at ways to leverage that resource and promote partnerships with industry to increase biomedical training opportunities for underrepresented groups. She invited EnHIP members to ask their local Congressional representatives for more resources to support these training and education measures.

IX. Discussion and Q&A with Dr. Le Fauve

Dr. Copeland asked whether the Scientific Workforce Diversity Office has thought about how to get more minorities in the pipeline at the high school level. Dr. Le Fauve responded that their budget mandate targets doctoral level or career level people. However, the office has been involved in a federal interagency committee focused on inclusion with the STEP-UP program. This program provides hands-on summer research experience for minority high school students interested in research careers. The committee also has other initiatives targeting even younger children. Dr. Copeland said recruiting black men into the medical school at Howard University has been very difficult. Dr. Le Fauve mentioned that her office is considering a partnership with the National Collegiate Athletic Association to steer African-American males on college athletic scholarships toward a science curriculum and eventually medical school.

Dr. Matthews-Juarez thanked Dr. Le Fauve for her presentation and invited EnHIP members to e-mail any further questions to Dr. Le Fauve.

X. Strategic Planning Session Introduction

The afternoon session began with discussion about the *All of Us* program and the many concerns of EnHIP members. Privacy and security issues dominated, but the overall lack of information available to EnHIP on many levels cut across all subjects and prevented members from lending unconditional support to the project. The consensus was that EnHIP must be a partner at the table, have a voice early in the process, and have access to the whole picture.

Specific concerns included the need for funding and infrastructure at the community level for engaging trusted community members to not only promote *All of Us*, but also to counsel participants as information is returned to them. Availability of funding and/or resources to enable truly equitable access to the data was also a concern, particularly for minority-serving institutions and other organizations without internal capacity to analyze the data. Several EnHIP members

commented on the general feeling of “What’s in it for me?” Even though they understood that *All of Us* has the potential to reveal important findings of benefit to minorities, both as individuals and as a group, the risks of unintended and unimagined consequences are substantial. Furthermore, simply having the information does not necessarily alleviate health problems or disparities. Mention was made of the genome-wide association study, which came with big promises that ultimately did not materialize. Despite these reservations, the EnHIP members did appreciate the fact that *All of Us* is an aspirational project and holds an opportunity for minorities to be represented in a major research project with the potential for addressing health care disparities and health equity.

Before breaking into groups to discuss development of a new EnHIP strategic plan, Dr. Matthews-Juarez advised the representatives that the next phase of the EnHIP work is to align its strategic plan with that of NLM, as well as to encourage member schools to adapt curricula and design training for the new generation of biomedical and health scientists. She asked the EnHIP members to think about how they will meet the objectives of the plan and how the objectives will be implemented in their institutions. Everybody was then assigned to one of three groups—one group for each of the three goals of the NLM strategic plan—and spent approximately one hour in discussion before reconvening.

XI. Report Back from Discussions on the EnHIP Strategic Work Plan

Group 3, which addressed the third goal of the NLM strategic plan, presented first, with Dr. Sarpong as spokesperson. The group looked at issues spanning all four objectives rather than approaching the objectives individually. Appendix A lists the group’s ideas with associated commentary from Dr. Sarpong. The group indicated that data science is somewhat of an unknown, prompting the suggestion of a catalog that explains what data science means and the requirements and training or education needed to enter the field. Training programs for faculty, counselors, librarians, and leaders at all grade levels, as well as mentoring and infrastructure support, were deemed to be important. In the same way that writing skills span across all subjects, data science is multidisciplinary and transdisciplinary, and the group felt that EnHIP partner institutions should intentionally integrate data science across the curriculum.

Dr. Matthews-Juarez added that the heavy burden of student loans can discourage potential candidates from pursuing an education in science, technology, engineering, and mathematics (STEM) majors. She and Dr. Sarpong suggested a competitive process for scholarships, either through government agencies or perhaps industry, and less burdensome loan repayment terms. Dr. Sarpong also observed that many STEM graduates end up working in fields unrelated to STEM, including students who are pre-med but do not go to medical school. He felt that these were strong candidates for redirecting to library science master’s degrees. Dr. Paul B. Tchounwou, Jackson State University, agreed and pointed out that just retaining students in STEM majors could make a big impact. Finally, Dr. Warren recommended casting a wider net to include not just STEM majors but science, technology, engineering, arts, and mathematics (STEAM) majors.

Group 1 presented next, with Dr. Sydnor as spokesperson. This group addressed the first goal of the NLM strategic plan and chose to reprioritize the four objectives to reflect what they felt was most important. Appendix A lists the group’s ideas, in the order presented, with associated

commentary from Dr. Sydnor. They envisioned EnHIP advising NLM with respect to ensuring accessibility of digital resources to a wide spectrum of audiences, and they also believed EnHIP could serve as a conduit for NLM to develop institutional capacity for research at MSIs. They suggested that EnHIP could identify the principles and values that shape open science policies and could develop a broad-based framework for achieving open science policies and practices. The group also identified two action items: (1) request NLM funding to support additional meetings necessary to build relationships and networks, and (2) request NLM funding to allow EnHIP members to pool data and determine future research needs as well as a research agenda to meet those needs. Dr. Matthews-Juarez advised that requests for funding should suggest a possible funding stream. She also said that a timeline with milestones would be helpful, as would be a list of who (not just individuals, but organizations) would be responsible for each activity.

The last report came from Group 2 and was presented by spokesperson Dr. Smith-Hendricks. Appendix A lists the group's ideas with her associated commentary. Many creative ideas were presented for connecting with people "where they are." Having fun and tapping into natural curiosity, familiarity, trust relationships, and rewards systems undergirded many of the suggestions. In order to engage NLM users, the group noted the importance of identifying what the target audience *needs* to know and then finding the intersection with what they want to know. They proposed methods of engagement ranging from public service announcements and games to social marketing and intentional micro messaging. They also emphasized the importance of using trusted intermediaries, such as popular opinion leaders or community health workers, to convey health information to a community. Their ideas for enhancing information delivery included updating science-based games on the NLM Web site, exploring a partnership with Google, and assembling an NLM junior board to evaluate NLM Web sites.

Dr. Matthews-Juarez congratulated the EnHIP representatives for their excellent work and thanked Ms. Janice Kelly for acting as scribe. A collective record of the suggestions will form the core of an EnHIP work plan, which the representatives will need to further develop to include resource needs, responsible parties, expected outcomes with benchmarks, and timelines. Dr. Matthews-Juarez recommended that EnHIP members share the work plan, once it is completed, with others on their campuses and solicit ideas and guidance to refine it, while at the same time stimulating interest in EnHIP. This could serve as a recruitment strategy for new EnHIP representatives and a means of obtaining support for the work of EnHIP. Dr. Withers remarked that EnHIP needs to find out what learning modalities the NLM already has, and how that information can be distributed regularly to the EnHIP membership. Ms. Maletta Payne, Southern University at Baton Rouge, explained LibGuides, which are electronic subject guides that pull together all types of information about a particular subject. These can be shared with the public and are an effective tool for distributing information.

Dr. Matthews-Juarez introduced the topic of branding and getting the word out about the work EnHIP does. She thanked Ms. Cynthia Gaines of the NLM Division of Specialized Information Services for producing a one-page summary fact sheet (Appendix B) to help publicize the work of EnHIP. Dr. Matthews-Juarez believes EnHIP can assist NLM in more ways than it already does, however, and she suggested the possibility of a cooperative agreement between EnHIP and NLM. EnHIP could be an effective conduit for getting information into communities and for assisting with issues of Tribal health. As EnHIP formulates its strategic plan for the next ten years, Dr.

Matthews-Juarez asked the representatives to think about how EnHIP can align its work with the work NLM is doing not only regionally but also in their own communities.

The discussion concluded with a suggestion from Dr. Sarpong to continue the conversation around the strategic plan via conference calls or other means. He and Dr. Bauer thought small-group efforts, perhaps using the EnHIP strategic plan subgroups, could facilitate progress toward a collective product, and Dr. Matthews-Juarez agreed. In closing, Dr. Warren reflected on the work done that day and the work that lay ahead: “As I listened to the various groups, we moved from a feeling of lack—that is, what we need, what we don’t have—to a sense of abundance—what we want and what we can do. As we leave, we can think more about what we do have, and we’ll have a very fruitful tomorrow.”

Day 2

XII. Travel Reimbursement and Welcome

Ms. LaFrancis Gibson, Oak Ridge Associated Universities (ORAU), began the day with details about travel reimbursement and asked participants to fill out paperwork. Dr. Patricia Matthews-Juarez, Meharry Medical College, then welcomed everyone to the second day of the annual meeting. Dr. Rueben C. Warren, Tuskegee University, reminded participants that the meeting focus would be transitioning to what EnHIP has done and is doing now.

XIII. New EnHIP Strategic Work Plan

The main agenda for Day 2 was developing the EnHIP strategic work plan. Dr. Matthews-Juarez developed an outline for the work plan with the following elements: introduction, mission, vision, objectives, strategy/work plan, evaluation, and summary. She indicated that the report should be structured to align with the goals and agenda of the NLM Strategic Plan 2017–2027. The outline began with an introduction, which Dr. Matthews-Juarez suggested they write later, once they decided how to frame the report. The mission statement as it is currently written¹⁰ focuses on environmental science, but EnHIP has a broader scope now. Dr. Doris Withers, Medgar Evers College, CUNY, advised that the mission statement should be more reflective of the NLM Strategic Plan and what EnHIP is doing today. An extended discussion followed, with various opinions expressed on what a mission statement should be and the precise wording to use. The group contemplated the three pillars of the NLM (as written in the NLM Strategic Plan) and agreed that a mission statement should be concise and timeless. As Dr. Withers pointed out, visions change over time, but missions should remain essentially the same unless an organization is at a major turning point. That said, she also believed it is time to revise the current EnHIP mission statement, keeping in mind that it must articulate the EnHIP mission for the next ten years. The EnHIP representatives eventually settled on the following wording:

¹⁰ 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.

Mission: The mission of the Environmental Health Information Partnership is to enhance the capacity of minority-serving academic institutions to acquire, use, and disseminate environmental health information and to promote and expand data driven science.

Dr. Matthews-Juarez next turned the discussion to development of a vision statement. The group put forth a wide range of ideas and wording preferences, with many small-group discussions and presentations of concepts and ideas. In the interest of time, Dr. Matthews-Juarez proposed the following wording with assurance that EnHIP representatives would have an opportunity to edit the wording later:

Vision: Building the capacity of minority-serving institutions to promote education and development of research aimed at reducing health disparities and fostering health equity on campus and in communities through partnership with NLM.

The five EnHIP objectives as currently written on the NLM fact sheet (Appendix B) were considered still relevant by the group members. They agreed that the objectives line up with where EnHIP is today as a group. Dr. Matthews-Juarez proposed a sixth objective to reflect the new data science theme of the NLM Strategic Plan 2017–2027. The discussion that followed attempted to clarify the wording, with some differences of opinion on what the objective actually means. The following wording was accepted by a majority of the EnHIP members:

Objective 6: Build capacity for data driven science on minority-serving institution campuses and in their communities.

An important feature of the NLM fact sheet for EnHIP is the summary of accomplishments. Dr. Matthews-Juarez asked Ms. Gibson and Ms. Janice E. Kelly, Division of Specialized Information Services, NLM, to collect (after the meeting) from each school a list of accomplishments funded through the EnHIP outreach awards program. The members were then invited to share with the group one or more accomplishments, which ranged from public events to promote health literacy and health-related careers to curriculum development and other academic efforts and collaborations to stimulate interest in, and use of, NLM resources. Everyone expressed appreciation for the funding and attributed many of their accomplishments to the EnHIP outreach awards program. Ms. Cynthia Gaines, Division of Specialized Information Services, NLM, noted that NLM likes to see publications, and Dr. Warren, Dr. Paul Tchounwou (Jackson State University), and Dr. Matthews-Juarez responded with information about various journals and publication efforts they have been involved with. Ms. Gaines also mentioned two networking events that EnHIP members should consider attending: the American Medical Informatics Annual Symposium in November, and the National HBCU Braintrust forum held during the annual legislative conference of the Congressional Black Caucus Foundation. Dr. Daniel Sarpong, Xavier University of Louisiana, added that the 12th Health Disparities Conference hosted by Xavier University's Center for Minority Health and Health Disparities would be held April 8–10.

EnHIP currently has 22 participating institutions, with representation from HBCUs, Tribal colleges, and Hispanic-serving institutions. Dr. Matthews-Juarez asked the attendees to think about

other institutions they should invite to participate. Ms. Gaines commented that Dr. Patricia F. Brennan, Director of NLM, would like to see some smaller colleges included. Dr. Milton A. Morris, Benedict College, said only four HBCUs have accredited environmental health curricula, and two are already members. The other two are North Carolina Central University and Mississippi Valley State University. Dr. Warren suggested Tougaloo College and Talladega College, and Dr. Matthews-Juarez suggested Tennessee State University, all of which are HBCUs. Dr. Matthews-Juarez also suggested Northeastern State University in Oklahoma because they work with various Tribes. Dr. Stephanie Bauer, University of Alaska Anchorage, suggested the University of Alaska Fairbanks because they are involved in the Alaska Native healthcare program. Ms. Ann Krejci, Oglala Lakota College, recommended that EnHIP ask Dr. David Wilson of the NIH Tribal Health Research Office about other possible Tribal college partners.

XIV. Strategies for Investing in the Future

The final part of the meeting was an opportunity to think about ways EnHIP can reach a bigger audience and motivate people to use NLM resources. The members agreed that a more proactive approach to attending conferences, where they can distribute the EnHIP fact sheet and talk with interested parties, would be a good place to start. The EnHIP representatives asked Ms. Gaines and Ms. Kelly to provide a list of conferences that NLM will attend and have a booth at over the next year and asked Ms. Gibson to ensure that EnHIP fact sheets will be available at the booth.

Dr. Matthews-Juarez commented that the EnHIP outreach awards program has been highly effective and should be continued. She also thought that EnHIP partner institutions should make a more concerted effort to partner with public libraries and medical libraries—both local and regional—with the help of the NNLM where needed. Dr. Withers would like to see EnHIP fact sheets, perhaps quarterly, that members could distribute on their campuses to promote health literacy. As examples, she mentioned “Did you know?” fact sheets and a fact sheet for Earth Day with resources people could access on the NLM Web site. Dr. Withers also proposed a “hands-on” activity to familiarize people with NLM resources, and Ms. Kelly responded that NLM can arrange Webinars that anyone may attend. Ms. Maletta Payne, Southern University at Baton Rouge, suggested that lists of NLM resources applicable to different majors, especially free resources, could be a very useful tool for faculty, and librarians could act as the distribution point for those lists.

Dr. Matthews-Juarez added to the discussion by suggesting that an online presence for EnHIP would be helpful. One idea was for members to write a blog or use their Web site to highlight the EnHIP-related work being done on their campuses and in their communities. For example, for National Library Week, members could ask their institutional marketing departments to highlight an EnHIP-funded program and related NLM resources. Dr. Bauer made the case for a single, central Web page featuring a description of EnHIP, plus project highlights and links to the EnHIP partners and their work. The U.S. Department of Health and Human Services does have an EnHIP Web page, but the site is not very engaging. Dr. Matthews-Juarez suggested links to funding opportunities, or short snippets of engaging conversations. The EnHIP representatives agreed that the partnership must make better use of technology to reach the next generation and must encourage the EnHIP partner institutions to build capacity and infrastructure for technology.

XV. Closing Remarks

Dr. Bauer reminded the conference attendees that Ms. Kelly will be retiring in June, and everyone thanked Ms. Kelly for her eight years of service to EnHIP. Dr. Matthews-Juarez offered thanks to Ms. Gaines and Ms. Kelly for planning the annual meeting, and to the ORAU team for coordinating the logistics. She also thanked Dr. Brennan for her continued commitment to EnHIP, and she expressed appreciation to the EnHIP representatives for taking the time to attend the meeting.

Dr. Warren closed with words of hope that EnHIP can find a way to function as a unit throughout the year and use the collective strength of the group to excel. The meeting was adjourned at 11:34 a.m.

APPENDIX A

Environmental Health Information Partnership Meeting—April 3–4, 2019

- Group 1: Dr. Robert Valdez, University of New Mexico (facilitator)
Dr. Robert L. Copeland, Jr.
Dr. Kim Sydnor
Dr. Syreeta Tilghman
- Group 2: Dr. Sandra Harris-Hooker, Morehouse School of Medicine (facilitator)
Ms. Dolores E. Caffey-Fleming
Dr. Betty Damask Bembenek
Dr. João Ferreira-Pinto
Ms. Judith Mazique
Dr. Milton A. Morris
Dr. Constance Smith-Hendricks
- Group 3: Dr. Daniel Sarpong, Xavier University of Louisiana (facilitator)
Dr. Stephanie Bauer
Ms. Ann Krejci
Ms. Maletta Payne
Dr. Paul B. Tchounwou
Dr. Doris Withers

APPENDIX A

Environmental Health Information Partnership Meeting—April 3–4, 2019

Goal 1: Accelerate discovery and advance health through data-driven research

Objective	Group Ideas	Comments
1.3: Foster open science policies and practices	EnHIP will identify the principles and values around open science policies and will provide guidance in the form of a broad-based framework that can be tailored for each institution's principles	Group 1 reprioritized the objectives: 1.3, 1.4, 1.1, and 1.2
1.4: Create a sustainable institutional, physical, and computational infrastructure	EnHIP will position itself to serve as a conduit for NLM to develop institutional capacity among MSIs in support of the advancement of research	Need additional funding for convening to discuss how to implement this and build relationships across the EnHIP networks
1.1: Connect the resources of a digital research enterprise	EnHIP will serve in an advisory role to ensure NLM increases accessibility of digital resources to a wide spectrum of audiences at the individual and institutional level	Resources may be digital, but the translation may not be; increase data uptake by translating digital information into a useful form for the user
1.2: Advance research and development in biomedical informatics and data science	EnHIP will facilitate non-siloed research and promote the use of both big data and small data sets	Need additional funding for EnHIP to create and pool data to assess where future research needs are and develop a common research agenda

Goal 2: Reach more people in more ways through enhanced dissemination and engagement

Objective	Group Ideas	Comments
2.1: Know NLM users and engage with persistence	Use a broad range of communication strategies: <ul style="list-style-type: none"> • public service announcements, such as the radio, bus placards, billboards, park benches • social media — tweets, texts; brief and to the point • games and videos • social marketing – target specific groups and vary the approach/delivery depending on the user's age and other characteristics • intentional micro-messaging 	Identify what the target audience needs to know—not all the things we want them to know—and hope that it intersects with what they want to know

APPENDIX A

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Objective	Group Ideas	Comments
2.2: Foster distinctiveness of NLM as a reliable, trustable source of health information and biomedical data	<ul style="list-style-type: none"> • Use trusted intermediaries to engender confidence in the message: <ul style="list-style-type: none"> ○ trusted community persons or leaders – use train-the-trainer or peer trainers to train them ○ popular opinion leaders – train them and let them be agents of change ○ our community connections – teach them about NLM ○ community health workers, especially those working in middle or high schools – kids are interested in health and become health advocates for their friends and families • Use TED talks or YouTube-type formats • Place the NLM link on major Web sites; research libraries should reach out to local or K-12 libraries to make sure the NLM link is on their Web sites 	The key is to foster trust
2.3: Support research in biomedical and health information access methods and information dissemination strategies	<ul style="list-style-type: none"> • Train middle school and high school students in basic research skills, such as literature reviews – tailor to their grade level • Use evidence-based practice or STEM results to pique curiosity and spark interest in research outcomes • Use a reward/recognition program to encourage use of resources • Create a loyalty program for kids so they can redeem earned points 	Need funding to support and promote research
2.4: Enhance information delivery	<ul style="list-style-type: none"> • Update/revise science-based games on the NLM Web site • Solicit feedback on programs at related sources (NIH, CDC) and connect the good ones with the NLM Web site • Entice university professors to use NLM as their 1st resource • Conduct a survey to determine the benefits of using NLM vs. Google Search • Explore a partnership with Google and get them to disseminate information • Use an NLM junior board to evaluate NLM Web sites; rotate membership among high school students and develop a recognition program with T-shirts and certificates; reward the best evaluators with a trip to the NLM facility in Bethesda 	

APPENDIX A

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Goal 3: Build a workforce for data-driven research and health

Objective	Group Ideas	Comments
3.1: Expand and enhance research training for biomedical informatics and data science		
3.2: Assure data science and open science proficiency		
3.3: Increase workforce diversity		
3.4: Engage the next generation and promote data literacy	<ul style="list-style-type: none"> • Build infrastructure for all of the objectives • Train the faculty, counselors, and teachers (train-the-trainer model) at college and K-12 levels to redirect the pipeline toward data-driven science • Promote partnerships between colleges and K-12 schools • Work on interfacing with university/college leadership to secure resources and time for faculty to do research and take additional training (get NLM help with this) • Make a catalog of what data science means and the requirements and training/education needed to enter the field; NLM could make this; EnHIP could use it as a resource to educate their communities • Provide intensive summer certification programs for faculty • Revisit curricula in EnHIP partner institutions to integrate data science • Educate faculty and communities about the data sources available, where to find them <i>and</i> how to use the data for recreational or research purposes; a data symposium or Webinar might work • Engage librarians to be local resources, knowledgeable about data sources and data science careers • Identify resources to run big data sets – collaborate with bigger universities or partner with business sector • Support workforce diversity through development of infrastructure and resources at minority institutions and through strategies for inclusion of minorities • Support mentoring • Reduce the financial burden of student loans by offering more scholarships for data science majors or securing more favorable loan repayment terms • Devise a strategy to retain students in STEM majors or redirect pre-med students into data science careers 	Group 3 did not separate tasks by objective because many of the tasks span several objectives

APPENDIX B

Environmental Health Information Partnership Meeting—April 3–4, 2019



U.S. National Library of Medicine®

Environmental Health Information Partnership

Overview

The National Library of Medicine's 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. EnHIP evolved from the Toxicology Information Outreach Panel (TIOP) which was established in 1991 in response to the pressing issue of toxic waste and the exposure to toxic chemicals in minority communities.

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.

History

This partnership began as a pilot project in 1991 as the Toxicology Information Outreach Panel (TIOP). During the late '80s, and early '90s, a number of published articles and books highlighted the adverse effects of environmental hazards on minority and socioeconomically deprived communities.

A clear need existed for toxicology and environmental health information to be more readily accessible to health professionals serving these communities. Recognizing this need, the National Library of Medicine launched TIOP to strengthen the capacity of HBCUs to train medical and other health professionals in the use of toxicology, environmental, occupational, and hazardous waste information resources.

The value and success of the project later led to the Library's longest-standing outreach program. The name was changed to the Environmental Health Information Outreach Program (EnHIOP) to reflect the diversity of the participating institutions. In 2008, the name was changed to Environmental Health Information Partnership (EnHIP) to reflect a true partnership with NLM. The Partnership reflects a broader focus on the multiple dimensions of environmental health, the environmental health sciences, and health disparities.

Objectives

- **Institutionalize** the NLM resources through incorporation of resources in the curriculum, seminars, and special events at each institution with high-level administrative and academic involvement
- **Strengthen** institutional partnerships with libraries and other entities such as environmental justice centers, poison control centers, drug information centers, and centers of excellence
- **Develop** and strengthen relations with local agencies and community-based and faith-based organizations to extend health-related outreach to communities surrounding the participating institutions
- **Increase** participation in professional meetings and public forums through presentations, posters, and panel discussions, and seek opportunities for publication in major journals
- **Serve** as NLM local and regional resources for training, exhibiting, and community outreach in order to promote the awareness and utilization of NLM resources

APPENDIX B

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Environmental Health Information Partnership

Accomplishments

Accomplishments of EnHIP include the creation of doctorate degree programs in environmental toxicology and environmental sciences, and doctorate and master of public health programs at a number of HBCUs. In addition, accomplishments include increased technology enhancement at participating schools and curricular technology development in information. Every year, students and faculty are trained to access health information, and faculty members have increased the publication of articles, papers, and books in the scientific literature.

Partnership Outlook

Future plans for EnHIP include

- Building collaboration among minority-serving institutions
- Incorporating disaster preparedness and emergency planning
- Explore ways to meet the challenges of climate science
- Finding solutions to environmental and social injustice
- Implementing a strategic plan that aligns with the vision and strategic plan of NLM

Contact Us

Learn more about EnHIP at:

<https://sis.nlm.nih.gov/outreach/enhip.html>

E-mail:

tehip@tehl.nlm.nih.gov

Toll Free:

1.888.FIND.NLM (1-888-346-3656)

www.nlm.nih.gov



Rev. 2-2019

Participating Institutions

Benedict College, Columbia, SC

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

Colorado Mountain College, Glenwood Springs, CO

Florida A&M University, Tallahassee, FL

Hampton University, Hampton, VA

Haskell Indian Nations University, Lawrence, KS

Howard University, Washington, DC

Jackson State University, Jackson, MS

Medgar Evers College, CUNY, Brooklyn, NY

Meharry Medical College, Nashville, TN

Morehouse School of Medicine, Atlanta, GA

Morgan State University, Baltimore, MD

Navajo Technical University, Crownpoint, NM (main campus)

Oglala Lakota College, Pine Ridge, SD

Southern University at Baton Rouge, Baton Rouge, LA

Texas Southern University, Houston, TX

Tuskegee University, Tuskegee, AL

University of Alaska Anchorage, Anchorage, AK

University of New Mexico, Albuquerque, NM

University of Puerto Rico, Medical Sciences Campus, San Juan, PR

University of Texas at El Paso, El Paso, TX

Xavier University of Louisiana, New Orleans, LA

APPENDIX C

Environmental Health Information Partnership Meeting—April 3–4, 2019

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

*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.

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Environmental Health Information Partnership Meeting—April 3–4, 2019

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, 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 that 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: NLM's 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 groups, 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.

Henry Lewis III, Professor and Dean
College of Pharmacy and Pharmaceutical Sciences
Florida A&M University, Tallahassee, Florida
Chairman, National Library of Medicine Environmental Health Information Partnership

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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.

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 1. 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.

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- 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.
- 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.

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- Use data from the preceding objective as the basis for a seminar/discussion on the development of electronic health records, including presentations of case studies in which health records were essential sources 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—April 3–4, 2019

ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP MEETING

April 3–4, 2019

DIRECTORY OF GUEST SPEAKERS

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APPENDIX E

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ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP MEETING

April 3–4, 2019

BIOGRAPHIES

Patricia Flatley Brennan, RN, PhD, is 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 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.

Patricia Matthews-Juarez, PhD, is Meharry Medical College's senior vice president for 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.

Rueben C. Warren, DDS, DrPH, MDiv, is 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 an associate professor and dean 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 both master's and doctorate degrees 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.

Charlene E. Le Fauve, PhD, became the first senior advisor to the National Institutes of Health (NIH) Chief Officer for Scientific Workforce Diversity (COSWD) in December 2016. In this role, Dr. Le Fauve supports Dr. Hannah Valentine, who serves as the NIH COSWD as she leads the NIH effort to diversify the biomedical research workforce by developing a vision and comprehensive strategy to expand recruitment and retention, and promote inclusiveness and equity throughout the biomedical research enterprise. Dr. Le Fauve came to COSWD from the National Institute of Mental Health (NIMH), where she served as deputy director of the Office for Research on Disparities and Global Mental Health. Prior to joining NIMH, she was a senior policy coordinator at the Department of Health and Human Services, where she led coordination and clearance activities of regulations, policy, and other reports for the Centers for Medicare and Medicaid Services and for implementation of the Patient Protection and Affordable Care Act. Her federal career spans 20 years and includes leadership and health scientist roles at the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, the White House Office of National Drug Control Policy, and the Substance Abuse and Mental Health Services Administration.

Dr. Le Fauve studied clinical psychology and behavioral medicine at the University of Georgia after completing her undergraduate education at Howard University. She completed her post-graduate work in the field of addiction medicine with an emphasis on perinatal addicted women and the treatment of co-occurring mental illness, addiction, and chronic pain at the Medical College of Virginia/Virginia Commonwealth University (MCV/VCU). She then joined the faculty as an assistant professor of human genetics and psychiatry at MCV/VCU, where she conducted behavior genetic research on African-American adolescent twins and drug use as an NIH principal investigator on a Research Career Development Award, and trained genetics counseling students, psychiatry residents, and psychology interns in cultural diversity and clinical practice.

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Dara Richardson-Heron, MD, chief engagement officer of the *All of Us* Research Program, is leading efforts to engage and retain one million or more volunteers in a landmark effort to advance innovative health research that may lead to more precise treatments and prevention strategies. *All of Us*, a cornerstone initiative of the NIH, aims to build one of the largest biomedical data sets in the world, involving participants from diverse communities across the United States. Dr. Richardson-Heron is responsible for forging partnerships with research participants, health care professionals, and national and community-based organizations to raise awareness of the program, with a special focus on populations that have been historically underrepresented in research. She is also working with the NIH and *All of Us* senior leadership team to develop strategies for creative and innovative programmatic efforts and enhancements.

Dr. Richardson-Heron has more than 20 years of leadership and management experience in the health care, corporate, and nonprofit sectors, having served in executive leadership positions at YWCA USA, Inc., Susan G. Komen for the Cure, United Cerebral Palsy Association, and Consolidated Edison of New York, Inc.

Dr. Richardson-Heron is a physician by trade and an advocate by choice who is passionate about leveraging her skills, experience, and expertise to make the world a better place. She holds a doctorate in medicine from New York University School of Medicine and a bachelor's degree in biology from Barnard College.

Amanda J. Wilson, MS, is head of the National Network Coordinating Office (NNCO) at NLM, which coordinates the National Network of Libraries of Medicine (NNLM). The mission of the NNLM is to advance the progress of medicine and improve the public health by (1) providing all U.S. health professionals equal access to biomedical information, and (2) improving the public's access to information, enabling them to make informed decisions about their health and healthcare. One of the major accomplishments of Ms. Wilson's tenure at NNCO is the establishment of a new partnership between NLM and the NIH *All of Us* Research Program. The purpose of the partnership is improving consumer access to high quality health information in communities throughout the United States, specifically, by working with public libraries.

From December 2006 to January 2017, Ms. Wilson served as director of the National Transportation Library (NTL), an all-digital library. At NTL, she focused on building collections, data curation, increasing awareness of NTL collections and services, and coordinating the national network of transportation libraries. Prior to NTL, Ms. Wilson served as an assistant professor and metadata librarian at The Ohio State University Libraries. From 2016 to 2018, she served as chair of the federal scientific and technical information (STI) managers group. Ms. Wilson is also an adjunct professor in the Department of Library and Information Science at The Catholic University of America.

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David R. Wilson, PhD, is the director of the Tribal Health Research Office at NIH. The office coordinates research related to the health of American Indians and Alaska Natives (AI/AN) across the NIH institutes. The office was created in recognition of the importance of ensuring meaningful input from and collaboration with Tribal Nations on NIH programs and policies. The office supports the NIH Tribal Consultation Advisory Committee (TCAC), which advises the NIH on Tribal health research. The TCAC provides a forum for meetings between elected Tribal officials and NIH officials to exchange views, share information, and seek advice concerning intergovernmental responsibilities related to the implementation and administration of NIH programs.

Dr. Wilson comes to the NIH Office of the Director from the Department of Health and Human Services Office of Minority Health, where he served as public health advisor and the AI/AN policy lead. Dr. Wilson graduated with a PhD in molecular and cellular biology from Arizona State University. Dr. Wilson completed a three-year postdoc and served as a senior research scientist at the National Institute on Aging. He also serves as an adjunct professor at the Johns Hopkins School of Public Health at the Center for American Indian Health.

ENVIRONMENTAL HEALTH INFORMATION PARTNERSHIP

EnHIP PROJECTS 2018-2019

Benedict College, Columbia, South Carolina

Minority College Students' Use of NLM Databases to Research Zika Viruses and Other Emerging Pathogens for Campus and Community Awareness

The goals of this project are to increase awareness of NLM resources among students within the college's science and public health programs and improve students' ability to present important contributions of NLM databases. This project continues the protocol of enlisting minority college students instructed in the use of NLM databases to research topics of priority for strategic planning by NLM. Students involved in this project will be required to research and make electronic presentations to faculty members and fellow students based on their use of NLM resources.

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

Using Environmental Data to Improve Health Outcomes in Our Community

The overall goal of this program is to provide environmental health and environmental justice information to promote health information literacy and reduce health disparities. The program will host a series of training sessions for students from the King/Drew Medical Magnet High School on environmental health information available from NLM. Upon completion of the training, students will attend meetings of community organizations to demonstrate the use of NLM resources and help train members of these organizations.

Colorado Mountain College, Glenwood Springs, Colorado

Immigrant Access to Environmental Health Resources and Career Training in Rural Western Colorado

Fifteen immigrant women will take a home health course certifying them to be personal care attendants (PCA). PCA training will include NLM environmental health resources for consumers to promote healthier lifestyle choices and address environmental health issues and health disparities.

Meharry Medical College, Nashville, Tennessee

Collection of Data for the Development of Community Health Maps to Highlight a Health Disparity, Environmental Issue, or Public Health Issues

The overall goal of this project is to engage middle school students and their parents, along with teachers, librarians, environmental public health faculty, Meharry health professions students, public health officials, and Tennessee Department of Transportation (TDOT) officials in a coordinated effort to identify and map for publication the best, safest routes allowing students to walk and bike to school and their public libraries in Nashville/Davidson County. Participants in the project will be taught how to access data from the NLM website to help determine the best and safest routes.

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University of Alaska Anchorage, Anchorage, Alaska

Improving Science-Ethics Communication at the Nexus of Climate-Food-Water-Energy-Health: Community Outreach Project That Engages Elementary School Children in the Anchorage School District

This project addresses the urgent need for more effective science-ethics communication in environmentally critical regions in the Circumpolar North. This project builds on the results of previous successful EnHIP outreach awards (2012; 2016), which underscore the need for such community engagement. The project will invite elementary school children in the only Arctic state in the United States to consider how values and public expectations play in the decision-making process that impact them as citizens at the nexus of climate-food-water-energy-health. University of Alaska Anchorage students will help design age-appropriate course and curricula materials that introduce the school children to values-aware and evidence-based research using NLM resources. They will work with classroom teachers, librarians, and principals to disseminate content during school visits and the public symposium.

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PICTORIAL HIGHLIGHTS



**National Library of Medicine Environmental Health Information Partnership Meeting
April 3-4, 2019**



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