

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL LIBRARY OF MEDICINE  
MINUTES OF THE BOARD OF REGENTS  
September 25-26, 2018**

The 179<sup>th</sup> meeting of the Board of Regents (BOR) was convened on September 25, 2018, at 9:00 a.m. in the Donald A.B. Lindberg Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), in Bethesda, Maryland. The meeting was open to the public from 9:00 a.m. to 2:30 p.m., followed by a closed session until 4:00 p.m. On September 26, 2018, the meeting reopened from 9:00 a.m. to 12:00 p.m. The meeting adjourned at 12:00 p.m.

**MEMBERS PRESENT** [Appendix A]

Ms. Jane Blumenthal, University of Michigan  
Dr. Eric Horvitz, Microsoft Research  
Dr. Carlos Jaen, University of Texas Health Science Center at San Antonio  
Dr. Daniel Masys, University of Washington  
Dr. Gary Puckrein, National Minority Quality Forum  
Dr. Jill Taylor, New York State Department of Health [Chair]

**MEMBER NOT PRESENT**

Dr. Alessandro Acquisti, Carnegie Mellon University

**CONSULTANTS PRESENT**

Dr. Suzanne Bakken, Columbia University  
Dr. S. Claiborne Johnston, The University of Texas at Austin  
Mr. Neil Rambo, NYU School of Medicine

**EX OFFICIO AND ALTERNATE MEMBERS PRESENT**

VADM Jerome Adams, Office of the Surgeon General, PHS  
Col. Kent DeZee, United States Army  
Dr. Joseph Francis, Veterans Health Administration  
Mr. Stan Kosecki, National Agricultural Library  
Capt. Matthew Lim, United States Navy  
Dr. Mary Mazanec, Library of Congress  
Lt. Col. Thomas Mahoney, United States Air Force  
Dr. Dale Smith, Uniformed Services University of the Health Sciences

**SPEAKERS AND INVITED GUESTS PRESENT**

Dr. Russ Altman, Stanford University (By Phone)  
Dr. Judith Dexhemimer, Cincinnati Children's Hospital  
Dr. Dara Heron-Richardson, Office of the Director, NIH

**MEMBERS OF THE PUBLIC PRESENT**

Dr. Barbara Redman, New York University/FNLM  
Mr. Thomas West, Krasnow Institute

## **FEDERAL EMPLOYEES PRESENT**

Dr. Patricia Flatley Brennan, Director, NLM  
Mr. Jerry Sheehan, Deputy Director, NLM  
Dr. Milton Corn, Deputy Director, Research and Education, NLM  
LCDR Christine Renee Adams, Office of the Surgeon General, PHS  
Ms. Anne Altemus, Office of Computer and Communications Systems, NLM  
Dr. Sameer Antani, Lister Hill Center, NLM  
Ms. Dianne Babski, Division of Library Operations, NLM  
Ms. Joyce Backus, Division of Library Operations, NLM  
Ms. Stacy Brody, Office the Director, NLM (Associate Fellow)  
Ms. Hua Florence Chang, Division of Specialized Information Services, NLM  
Ms. Sarah Clarke, Office of the Director, NLM (Associate Fellow)  
Mr. Ivor D'Souza, Office of Computer and Communications Systems, NLM  
Mr. Todd Danielson, Office of the Director, NLM  
Dr. Kathel Dunn, Division of Library Operations, NLM  
Dr. Valerie Florance, Division of Extramural Programs, NLM  
Ms. Kathryn Funk, National Center for Biotechnology Information, NLM  
Dr. Dan Gerendasy, Office of Health Information Program Development, NLM  
Ms. Rebecca Goodwin, Office of Health Information Program Development, NLM  
Mr. Daniel Hartinger, Office of the Director, NLM  
Dr. Michael Huerta, Office of Health Information Program Development, NLM  
Ms. Christine Ireland, Division of Extramural Programs, NLM  
Ms. Janice Kelly, Division of Specialized Information Services, NLM  
Ms. Elizabeth Kittrie, Office of Health Information Program Development, NLM  
Ms. Michelle Krever, Division of Extramural Programs, NLM  
Dr. David Landsman, National Center for Biotechnology Information, NLM  
Ms. Lisa Lang, Division of Library Operations, NLM  
Ms. Amelia Llorens, Office of the Director, NLM (Associate Fellow)  
Dr. Robert Logan, Office of Communications and Public Liaison, NLM  
Ms. Jennifer Marill, Division of Library Operations, NLM  
Dr. Clement McDonald, Lister Hill Center, NLM  
Ms. Grace Middleton, Office of Communications & Public Liaison, NLM  
Mr. David Nash, Office of the Director, NLM  
Dr. James Ostell, National Center for Biotechnology Information, NLM  
Dr. Dina Paltoo, Office of the Director, NLM  
Ms. Amy Powers, Office of the Director, NLM  
Mr. Eddie Rivera, Office of the Director, NLM  
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM  
Dr. Susan Speaker, Division of Library Operations, NLM  
Ms. Rebecca Stanger, Office of the Director, NLM  
Dr. George Thoma, Lister Hill Center, NLM  
Dr. Alan Vanbiervliet, Division of Extramural Programs, NLM  
Ms. Cecelia Vetter, Office of the Director, NLM (Associate Fellow)  
Ms. Amanda Wilson, Division of Library Operations, NLM  
Ms. Paije Wilson, Office of the Director, NLM (Associate Fellow)  
Dr. Fred Wood, Office of Health Information Program Development, NLM

## I. OPENING REMARKS

NLM BOR Chair, Dr. Jill Taylor, welcomed members, alternates, and guests to the 179<sup>th</sup> meeting of the Board of Regents. She introduced new BOR consultants: Suzanne Bakken, PhD, RN, Professor, Department of Biomedical Informatics, Columbia, University; Claiborne Johnston, MD, PhD, Dean and Vice President for Medical Affairs, Dell Medical School, University of Texas at Austin; and Neil Rambo, MLS, Retired Director, Health Sciences Library and Adjunct Curator, NYU School of Medicine; and Captain Matthew Lim, a new ex-officio member, Department of the Navy.

## II. MINUTES AND FUTURE MEETINGS

The Regents approved without change the May 2018 minutes. The next meeting will be held on February 12-13, 2019, and the spring meeting will be held on May 14-15, 2019. Also confirmed are September 10-11, 2019, February 4-5, 2020, May 12-13, 2020, and September 15-16, 2020.

## III. REPORT FROM THE NLM DIRECTOR

Dr. Brennan said the Board will divide into four working groups: *strategic planning*, *collections*, *research frontiers*, and *public services*. Each group will meet for an hour and a half today and report back on Wednesday. Dr. Brennan showed a short video on NLM's research prepared for the NIH Research Festival held earlier in September.

Dr. Brennan highlighted NLM health services research information and accomplishments since May 2018:

- To strengthen its focus on public health, NLM detailed Lisa Lang from LO/NICHR to OC/OHIPD as Assistant Director for Health Services Research Information.
- NLM is engaged in a 5-year development plan called *MEDLINE 2022* where automatic indexing is accelerated. The faster NLM automates, the quicker citations get to the public. 23% of PubMed is done through automated indexing first.
- NLM NNLM is partnering with *All of Us* program to assist in community engagement. An important element of this program is NLM's partnership with public libraries.
- NLM is supporting 10 next-generation new researchers and restored 43 training slots in its extramural PhD program.
- NLM trainees are now directing training program meetings. They identify speakers, bringing more engagement to the more than 250 people who meet each year.
- An NLM-wide IT assessment was undertaken to improve cataloging, standardization, security and performance measurement, and initiate shared services across NLM.
- NLM is working with NIH to accelerate data science. NCBI, together with CIT, have developed an Identity and Access Management Service, which should preserve identity and reduce the number of clicks it takes to find data at NIH.
- NCBI has also demonstrated rapid cross-cloud platform Sequence Data Delivery.

Dr. Brennan noted that the final report of the Blue Ribbon Panel, led by Russ Altman, PhD, will be presented to the Board later today.

Dr. Brennan said that a new organizational plan to help NLM achieve its Strategic Plan goals was presented to NIH and approved in August 2018. It details how NLM plans to achieve its goals in phases. An organizational change package is under review. Once approved, NLM will start implementing changes which will last for several years.

Dr. Brennan said phase one seeks to 1) align some content acquisition and curation teams, outreach, and technical groups across the library; 2) discontinue, merge, or continue key NLM products and services; 3) map workflows and jobs to address key product and service delivery; 4) reassign staff and space over time; 5) expand NLM OD on research, health data standards, data science, and open science, and 6) rename OHIPD to the Office of Strategic Initiatives.

Dr. Brennan described an initiative between NLM and the National Academy of Science, Engineering and Medicine (NASEM) to convene a government, industry, academic roundtable on *Incentives for Open Science Study: Forecasting Costs for Preserving, Archiving, and Promoting Access to Biomedical Data*. This committee of experts will develop a framework for forecasting long-term costs of data.

The 2019 NLM and NIH budget approved by the Senate would give NLM about \$14 million more than its 2018 budget, said Dr. Brennan.

Dr. Brennan introduced new personnel: Ms. Amy Powers, Ethics Specialist; Mr. Eddie Rivera, Budget Officer; Dina Paltoo, PhD, MPH, Assistant Director for Policy Development; Ms. Lisa Federer, Data Science and Open Science Librarian; Maryam Zaringhalam, PhD, AAAS Science and Technology Policy Fellow; Ms. Julie Silverman, head of Collection Development and Acquisitions; Ms. Samantha Tempchin, Chief Grants Management Officer; and Zoe Huang, MD, Chief Scientific Review Officer. New Associates were also introduced: Ms. Stacy Brody, Rutgers University; Ms. Sarah Clarke, Clarion University; Ms. Amelia Llorens, University of Texas; Ms. Cecelia Vetter, University of Maryland, College Park; and Ms. Paije Wilson, University of Iowa. NLM also has new trainees in Lister Hill: Munder Ben-Omran, Travis Goodwin; Peng Guo, PhD; Vinh Nguyen, PhD; and Demetres Williams, DMD, MPH.

In response to a question from Ms. Blumenthal about biomedical literature being a type of data needing preservation, Dr. Brennan said many types of data need to be considered. She encouraged nominating people to the NASEM study to ensure this gets considered.

Dr. Taylor asked Dr. Brennan how she is helping employees with reorganization. Dr. Brennan said she and NLM leadership have been explaining NLM's vision for the future with the staff through, for example, town hall meetings with staff every six months. Leadership attend the town hall meetings, make presentations, and answer questions. About 500 staff attend. In addition, she had met with the head of each division and the division staff in smaller groups. She does not anticipate a major shift in NLM's work force.

Dr. Francis said he assumed there was an organizational succession plan for retirements and staff changes. Dr. Brennan said NLM prides itself on organizational longevity, but as NLM modifies its structure, it may not have the same organizational needs. Dr. Masys asked if the net effect would be a targeted reduction in force. Dr. Brennan said no, NLM will grow. Dr. Masys said

growth is a wonderful context for change. Dr. Brennan said she and Mr. Sheehan told NIH leaders they expect additional growth of about 125 people. The challenge, said Dr. Brennan, isn't just having competitive opportunities, it also requires competitive salaries. NLM has staff that need salary equity and she is looking for ways to do this. She would take as many pathways to growth as possible.

Dr. Brennan asked Dr. Paltoo to present the legislative update. Dr. Paltoo informed the Board that NIH has developed a set of FAQs for the European Union (EU) General Data Protection Regulation (GDPR) to determine how this regulation will impact NIH research. Dr. Paltoo said that in July 2018, NIH released a Notice in the NIH Guide for Grants and Contracts regarding "Delayed Enforcement and Short-Term Flexibilities for Some Requirements Affecting Prospective Basic Science Studies Involving Human Participants," and in August 2018, NIH released a Request for Information (RFI) regarding "Registration and Results Reporting Standards for Prospective Basic Science Studies Involving Human Participants." The response period closes in November. NIH wants to learn what the standards are for reporting these studies, the definition of a clinical trial, and how that can be extended.

Dr. Paltoo said that the NIH Strategic Plan for Data Science was released in June. NIH intends to hire a Chief Data Strategist and NLM staff are involved in implementing the plan. Dr. Paltoo said the Marrakesh Treaty Implementation Act passed the Senate in June and was referred to the House Judiciary. It requires countries to make copyright exceptions to permit creating accessible formats (e.g. Braille and audiobooks), including music in text or notation.

NLM is also looking at the Well-Informed, Scientific, & Efficient (WISE) Government Act. It will require Federal access to scientific literature and other subscriptions. NLM is named as one of the relevant stakeholders to be consulted in the development of a report and survey.

Dr. Horvitz commented on issues involved in GDPR, noting NLM and NIH have unique resources and will need guidance. Mr. Sheehan said NIH and NLM are trying to find out how this regulation will affect research.

#### **IV. PERSONAL HEALTH RECORD FOR YOUTH EMANCIPATING FROM FOSTER CARE**

Dr. Judith W. Dexheimer, University of Cincinnati Children's Hospital Medical Center, discussed her project to create a personal health record for youth, 18 to 20 years of age, leaving foster care. The project is in its first year.

Dr. Dexheimer said there are 427,000 children in the custody of child protective services (i.e., foster care) in the US. Children remain in foster care an average 19 months, with 26% of children in foster care for 2 years or longer. Adolescents experience an average of 7 placement changes while in foster care, and about 5,000 youth leave foster care annually. States provide independent living programs prior to emancipation to help with the transition. Support for health care self-management is not provided, and teens in or leaving foster care are unable to access their medical records. While in custody, access to medical records is managed by caseworkers; foster youth report limited access to health information and caseworkers and caregivers report

not having sufficient health information for the children in their care. This lack of health information results in foster youth reporting no knowledge of how to access primary care, poor management of chronic conditions, and increased preventable disease. Providing health data from the electronic health record could improve health knowledge, care coordination, and patient outcomes in this vulnerable population. However, no sustainable system to provide personal health records (PHRs) to this vulnerable population has been developed. The objective of Dr. Dexheimer's research is to improve health outcomes and promote health behaviors in foster youth experiencing a transition from pediatric to adult healthcare.

As a critical step toward accomplishing this goal, the project will create and distribute a PHR for foster youth at age 18, and lay the necessary foundation to assess feasibility, which is essential for future studies seeking to examine whether providing a PHR changes health service utilization once youth leave foster care. The project will work with the community and providers to ensure that foster youth receive a PHR upon leaving foster care. This project will have a meaningful impact on child health outcomes by delivering health information when youth need it most.

Dr. Masys commented that this project makes you feel there is a little foster care in all of us, since most individuals suffer from fractured healthcare and lack of continuity. When this project gets beyond the design phase, the *All of Us* project may help with some of the project's information collection issues via its development of data extraction tools for EMRs. Dr. Francis stated that he works with homeless veterans and he, too, faces barriers for information-sharing and the need for certain privacy protections. Dr. Horvitz asked about long-term outcomes for youth coming out of foster care. Dr. Dexheimer said there are almost no longitudinal studies on foster youth. Dr. Horvitz said there appears to be a higher rate of homelessness and drug use among foster youth. Dr. Dexheimer added that research shows a higher rate of pregnancy and substance abuse among foster youth than those not in foster care. Dr. Puckrein wondered whether the Medicaid program maintains records on foster youth. Dr. Dexheimer said in Ohio, when a child comes into foster care, they get a new Medicaid number. If the foster youth is placed back in a home, they have to get a new number. When Dr. Puckrein asked if they are doing anything different with the sickle cell population in terms of the data collected. Dr. Dexheimer said they are not. Dr. Puckrein wondered if this project is scalable. Dr. Dexheimer said the first goal is to scale it in Ohio, then to the 33 states that use SACWIS. Lastly, Dr. Jaen asked if they are addressing the complexity of the medical record. Dr. Dexheimer said they are.

## **V. DISCUSSION WITH THE SURGEON GENERAL, PHS**

VADM Jerome Adams, U.S. Surgeon General, said the Corps has been around since President John Adams. Since then, there have been more than twice as many presidents as surgeon generals. He is the 20<sup>th</sup>.

In March, VADM Adams put out the first Surgeon General's Advisory in 13 years—on opioid overdose. Currently, a person overdoses every 11 minutes in the US. The majority overdose in a home environment, which means the country cannot rely on first responders to save those lives. The OSG needs everyone to carry Naloxone to stop this epidemic. A month after this advisory was released, national Naloxone sales went up 40%.

VADM Adams said the OSG's main focus now is the opioid epidemic, community health, and economic prosperity. He noted recruits aged 18-24 aren't able to enlist because of poor health concerns, which is a crisis for our armed services. We need to invest in healthy communities.

Dr. Masys asked the Surgeon General if there is an opportunity for information-based targeting for opioid use and if the library could use its NNLM field force and global reach to help. VADM Adams responded everyone has a role. He is frequently asked if it is the doctor's fault for over-prescribing. He said everyone will need to help and that opioids are addictive so people need to understand that addiction is a brain disease and that Naloxone is available and can save lives. He said the opioid epidemic is a tragedy but also an opportunity to build healthy communities.

Dr. Puckrein said there is no system to measure or evaluate healthy community programs—to identify best practices and what makes a difference.

VADM Adams told the Board to think about 1) E-cigarettes. Every community is grappling with this. People don't understand what it is and its impact, and 2) marijuana. There is a difference between recreational and medicinal use and how it's treated from a criminal justice point of view.

## **VI. TOWARDS AN AFRICAN INFORMATION ECOLOGY TO SUPPORT RESEARCH AND HEALTH**

Dr. Dan Gerendasy, Chief of NLM's International Programs, reported that NLM is working toward more sustainable biomedical information ecology in Africa to support NIH's mission and meet the needs of international researchers, clinicians, students and policy makers. NLM's goal is to collect and disseminate high-quality biomedical information by increasing access to NLM resources and providing ways for African researchers to augment those resources through peer-reviewed publishing venues and platforms. NLM's strategy includes workshops, training, support for African medical journals, and health communication.

NLM supports 20-30 workshops per year in Africa, covering library resources, scholarly writing, systematic reviews, journal editing, publishing, peer review, manuscript preparation, bioinformatics, health informatics, and telemedicine coordinated by a network of African medical librarians and medical journal editors.

NLM is working with 10 African medical journals in 10 countries: DRC, Ethiopia, Ghana, Kenya, Malawi, Mali, Sierra Leone, Rwanda, Uganda, and Zambia. The program involves partnerships between Northern and Southern (African) Journals. Northern journals include *Annals of Internal Medicine*, *BMJ*, *Environmental Health Perspectives*, *JAMA*, *The Lancet*, and *NEJM*. Older Southern journals become mentors to new journals in South-South relationships. Goals are to (1) improve journals' quality and operations; (2) enable research from African journals to become widely known and available through MEDLINE and other indexing services; and (3) develop regional expertise to support and train African editors, authors, and reviewers. NLM has been piloting *National Health Communication Networks* (HCN) in Uganda and plans to expand to Ethiopia and other countries. The purpose of the program is to build relationships between researchers, clinicians, journalists, policy-makers, and librarians through the creation of

HCNs. Each network will be coordinated by one of our African journal editors and supported by medical librarians, who will help stake holders access NLM resources to encourage evidence-based medical practices and policies, accuracy in journalism, and health literacy. It will consist of a series of workshops, a moderated listserv and blog, and working groups with different stakeholders. The groups will address professional development and standards, advocacy for open data, public service announcements, combating misinformation, and promoting local research to the public and those who determine funding priorities. Each National HCN Professional Development Working Group will coordinate outreach activities in their respective countries and act as a platform for other NIH Institutes' initiatives.

A three-year training program, the *Tanzanian Health Information Specialist Diploma Program*, has been accredited by the Tanzanian Ministry of Health and will matriculate about 75 Health Information Specialists per year. Graduates will be employed by the Ministry and placed in clinics, hospitals, schools, and training centers to provide evidence-based medical resources to clinicians; assist medical, nursing, and pharmacy students; provide appropriate information resources to patients and families; assist in the organization and management of medical records; and facilitate the transition to electronic records management systems. This program will be the first step in an educational pipeline to create a strong health informatics workforce in Tanzania. The *Moroccan Health Informatics Master's Program* will have a core curriculum and specialty modules for students and professionals wishing to focus on health information systems, telemedicine, EMRs, medical library sciences and information management. The School of Information Sciences in Rabat (public) and Mohammed VI University of Health Sciences in Casablanca (private) are planning a partnership with experts from each institution. Our curriculum, approved by the Ministry of Education, will begin in November 2018.

Dr. Jaen asked why NLM was not doing this in Latin America. Dr. Brennan said this is a question for the *Research Frontiers* and the *Strategic Planning* groups. It would be helpful for NLM to know where its international outreach should be and where NLM should go from there.

Col. DeZee asked if NLM has partnered with the state department or anyone else in this work. Dr. Gerendansy said NLM initially connected with the State Department.

Dr. Francis asked if NLM is working with any countries to implement open source systems and Dr. Gerendansy said Morocco. With a master's program, they want to do a hackathon to build systems and they want master's students to participate and take ownership of the systems.

## VII. BOR WORKING GROUP REPORTS AND DISCUSSION

The Board heard reports from its four working groups: **Public Service:** Col. Kent DeZee, Dr. Alessandro Acquisti, Dr. Gary Puckrein, Mr. Stan Kosecki, *Dr. Jim Ostell*, *Ms. Florence Chang* *Ms. Wanda Whitney*, and *Mr. Ivor D'Souza* (staff) **Strategic Planning:** Ms. Jane Blumenthal, Dr. Dan Masys, and Dr. Jill Taylor, and *Dr. Michael Huerta* (staff); **Collections:** Dr. Carlos Jaén, Lt. Col. Thomas Mahoney, Dr. Mary Mazanec, Dr. Dale Smith, Mr. Neil Rambo, *Ms. Joyce Backus*, *Kathryn Funk*, *Jennifer Marill*, *Dr. Dina Paltoo* (staff) **Research Frontiers:** Dr. Susan Bakken, Dr. Wayman Cheatham, Dr. James Deshler, Capt. Matthew Lim, Dr. Clay Johnston, Dr. Eric Horvitz, *Dr. Sameer Antani*, *Dr. Milton Corn*, *Dr. Valerie Florance*, *Dr. Dina*



*Demner Fushman, Dr. David Landsman, Ms. Rebecca Goodwin, Dr. Clem McDonald, Mr. Jerry Sheehan, Dr. George Thoma (staff).*

For the **Public Services** group, Col. DeZee spoke about public facing services NLM could provide to address social determinants of health. The group said public facing services should feature three dimensions: quality, defined as providing what other agencies do not have the resources and experience to provide; integrity, defined as providing health information services that NLM can do better than other agencies, as well as providing services other agencies either cannot do or have decided not to pursue; and appropriateness, operationally defined as meeting unmet health needs and providing health.

Following Col. DeZee's presentation, Dr. Brennan asked rhetorically: Is the role of the library to fill in where the health care delivery system failed?

Dr. Puckrein talked about providing health information to the 55% of Americans who have not graduated from high school. Dr. Puckrein said that the U.S. health industry has not targeted these populations well, and that NLM could play a national role in advancing health literacy with underserved populations. Like Col. DeZee, he suggested NLM partner with Federally Qualified Health Centers and other groups serving vulnerable populations. Dr. Puckrein also said that NLM should assist physicians serving underserved African and Hispanic American communities. Dr. Brennan noted the group's idea to partner with more external groups to provide needed health information is a constructive idea.

Dr. Jaen suggested tailored health information to underserved audiences be part of an effort to influence health disparities by changing the environment in which low income Americans live. Progress to deter health disparities depends on infrastructural issues, such as parks, bike lanes, and schools. Dr. Bakken noted education is key to address health disparities and suggested partnerships with early childhood educators. Dr. Brennan and Mr. Sheehan provided examples where NIH Institutes partner with child health educators.

For the **Collections** working group, Dr. Smith provided a handout of the 1992 collections policy, which needs revision. He said the group hopes to work with the Board on a new policy. Dr. Brennan noted the policy needs to encompass providing access and preservation. She noted there is a consistent budgetary struggle for resources for both collections and preservation. She noted the latter issue is a current and future core institutional challenge. Mr. Sheehan spoke about the importance of a policy covering what should and should not be collected.

Ms. Blumenthal noted that most external constituencies envision preservation as NLM's most important role. Dr. Brennan agreed, emphasizing that a new policy needs to encompass both the collection and curation of medical information and data.

In response to questions from the Board, Dr. James Ostell said new policies to archive medical data are overdue. He said the library's responsibility to collect and curate raw medical research data needs a policy review.

Dr. Brennan and Dr. Dan Masys discussed whether public accessibility should be required for all

preserved medical data and literature, i.e., is there value for data that is archived but essentially inaccessible. They agreed the latter issue needs to be addressed in considering a new policy. The Board briefly discussed a timetable to provide new collections policy recommendations that should not be rushed but would be important to consider in 2019.

For the *Research Frontiers* group, Dr. Horvitz said a broad theme of the group was the opportunity to align both internal and external grants research calls to be consistent with the Strategic Plan's goals and sub-goals. Dr. Horvitz cited some research opportunities for consideration, such as the transfer of electronic patient records between hospitals and medical centers and workshops for researchers to learn how to advance research by using aggregated electronic medical record datasets. Dr. Horvitz noted NLM also could provide leadership in research that uses machine learning to assess aggregated electronic medical record datasets.

Dr. Dan Masys noted a role for NLM is providing leadership in "synthetic derivative" research, which is when steps are taken to de-identify the full text of patient records to the extent that is impossible to identify a specific patient from a data set of patient records. While steps are important to ensure patient privacy, Dr. Masys noted the process might foster data analysis challenges that become the focus of new informatics research.

Dr. Brennan said the report raised the issue of how NLM can uniquely advance medical research using machine learning and assessing large data sets in ways that other agencies are not doing. Dr. Brennan noted NLM currently cannot access de-identified electronic patient records from the Veteran Administration and that there are significant holdouts for open science research, including some HMOs do not currently share de-identified electronic medical records.

For the *Strategic Planning* working group, Ms. Blumenthal reported an array of internal and external communication strategies to inform employees and stakeholders about NLM's strategic plan. She cited internal communication, including an NLM strategic plan council with representatives from each NLM division and periodic town meetings. Ms. Blumenthal noted the implementation of NLM's strategic plan will demand increasing Board attention as the plan impacts resources. The group is interested in how NLM monitors and assesses the strategic plan.

Ms. Blumenthal said the Board expects to be informed about the plan's progress, but it did not want to micromanage implementation. The working group believes the Board should be willing to assist in the plan's implementation, be a conduit for information, and address questions.

Dr. Masys noted NLM's 1985-86 strategic plan set the foundation for the creation of NCBI and that the current plan has yet to lead to a 'flagship project' that could lead to a transformative advance.

Dr. Brennan added NLM seeks to hire new staff who advance the strategic initiatives. She suggested this is a departure from the way NLM hired in the past.

In a *general discussion* about the groups, Dr. Jill Taylor noted this was the first time a Board meeting devoted time for the groups to convene and report to the full Board. A discussion ensued about how often the groups should meet during Board meetings and how much time should be

allotted. Dr. Brennan said the working group reports and ensuing discussions were stimulating and helpful. They discussed having more focus during the next Board meeting.

### **VIII. NLM PARTNERSHIP WITH ALL OF US**

Dr. Dara Richardson-Heron, the Chief Engagement Officer of the *All of Us* Research Program, said the program's mission is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us. The program has three primary objectives: 1) build and nurture trusted relationships with participants; 2) deliver a valuable, rich resource of data, which will be accessible in new ways; and 3) catalyze a robust ecosystem of researchers who really want to use the data that is collected.

Building a database of one million individuals' representative of the true diversity of the US requires creativity and innovation. The program is taking a transformational approach to diversity with a goal to achieve diversity of people, geography, health status, and data type. It is committed to ensuring all communities, particularly those historically underrepresented in research, participate in and benefit. This includes people who are healthy and sick and from all walks of life, socioeconomic backgrounds, and regions of the country. It also aims to collect a data from surveys, electronic health records, blood and urine samples, and wearable devices.

The *All of Us* program is different in many ways from traditional research. The 1 million volunteers in the program are its partners, not patients. The program empowers participants by providing access to information that's gathered over the course of the program so participants can use the information to learn about their health. As program partners, they will be involved in the development and collection of data and research. Participants are the heart and soul of the program. They'll have an opportunity to learn about their own health, including genetic information, personalized risk factors, and exposure.

The program has a data and research center where the data lives; a biobank at Mayo Clinic—a repository for processing and storing samples; a participant center that runs a portion of the program where individuals can enroll; and a participant technology systems center, which runs the website and mobile app that facilitates enrollment. Health care provider organizations (Regional Medical Centers, Federally Qualified Health Centers, and the VA) help enroll members and people that are outside their membership. And, the program has a communications and engagement component, which supports all of its marketing and design work, and community partners like the National Network of Libraries of Medicine.

The *All of Us* engagement strategy is multi-faceted, and utilizes health care providers, a participant center, and NIH engagement partners, such as community and faith-based organizations, provider-patient advocacy organizations, and NIH Institutes, like NLM.

The program protects privacy and security; safeguarding participants' identity and data is most important. Participants want to know what data will be collected and how it will be returned to them. They want assurance that their data is protected. The program has implemented privacy and security principles to ensure data is safe and protected.

*All of Us* has about 30 funded community and provider organizations in its network to increase awareness and program engagement. There are more than 40 non-funded partners who work to increase program awareness. They want to work with respected organizations, like NLM, who can meet potential participants where they are and serve as trusted program ambassadors.

Dr. Richardson-Heron gave an overview of their program goals 1) increase the capacity of public libraries to improve health literacy; 2) highlight public libraries as a technology resource for participants; 3) equip public libraries and member organizations with program information to share within the public; 4) assess the impact of libraries on participant enrollment and retention; and 5) establish an online platform for program education and training.

Dr. Richardson-Heron introduced Amanda Wilson, Chief of NLM's National Network of Libraries of Medicine, to share more information about NLM's partnership with *All of Us*. Ms. Wilson said goals for the NLM partnership with *All of Us* fall into three broad areas operated by two different centers within the NNLM: the Greater Midwest Region (GMR) at the University of Iowa and the Middle Atlantic Region (MAR) at the University of Pittsburgh. For community education, the network is reaching library audiences to focus on improving health literacy and community education activities. NNLM's aim is to train 200 public library staff in the coming year. NNLM is partnering with national library associations to raise awareness about the program; offering training, funding, and community connections for new public library partners; and partnering with *All of Us* consortium members for events. These activities fall under the NNLM *All of Us* Community Engagement Network, which consists of a subgroup of NNLM members who support, promote, or lead engagement activities for *All of Us* in libraries. For the third area of the partnership, the *All of Us* Training and Education Center has developed and is operating a learning platform for training and education about the *All of Us* Program.

Ms. Blumenthal said this is a great example of leveraging NLM resources and existing programs for this new endeavor. NLM is drawing in both traditional health sciences libraries as well as public libraries. She asked about orienting public librarians to answering health questions. Dr. Richardson-Heron said that the community and faith-based groups receive training. The program started in July with four funding partners: Delta Research and Education Foundation, the San Francisco General Hospital Foundation, 50 Forward, and the National Alliance for Hispanic Health. Realizing that four partners would not be enough, they began bringing on other partners. Now there are faith-based partners too. All receive a core training.

Ms. Blumenthal observed that this program expands the role of the Library from a place where you go to find information on a particular topic into actually providing health education. Dr. Horvitz added that the focus of *All of Us* appears to be on health literacy, engagement, and library resources, and less on building a big data set. He asked for comments about the work that goes into the collection side versus the literacy and engagement side. Dr. Horvitz also asked for Dr. Richardson-Heron to comment on the dataset and how they would have a viable dataset over the 10-year course of the project. Dr. Richardson-Heron explained that the program focuses on community engagement but the program goal to build the largest dataset for researchers remains. The program launched in May and now has over 100,000 participants; 60,000 of those are full participants meaning they have completed all of the surveys and provided the blood and urine specimens. About 70% are from under-represented research communities, a result of

community engagement.

Dr. Richardson-Heron said the program hopes to change the face of health care. Currently, partners provide the bulk of the 60,000 enrollees, but they are trying the direct volunteer approach where people can go to their local Walgreens or a Quest Diagnostic Center to provide their urine and blood specimens. They are piloting various approaches to see what works as this is an iterative process. They will test to make sure their vision is realistic, and make changes as needed.

## **IX. PRESENTATION OF THE REGENTS AWARD**

Dr. Taylor said the Board established the Regents Award in 1970 to recognize and stimulate independent creativity leading to scholarly or technical achievements in biomedicine. This award is the highest honor the Board can give to an NLM staff member.

Dr. Brennan announced that Dr. Robert Logan, a Social Science Analyst in OCPL, is a 2018 recipient of the Regents Award. He was recognized for co-editing the book, *Health Literacy, New Directions in Research, Theory and Practice*.

Dr. Brennan said that Dr. Susan Speaker, an historian with HMD, was the second recipient of the 2018 Regents Award. She was recognized for her work and outstanding scholarship in documenting the history of the National Network of Libraries of Medicine in the book, *A Historical Overview of the National Network of Libraries of Medicine, 1985-2015*.

## **X. ADJOURNMENT**

Dr. Taylor adjourned the Board of Regents meeting at 12:00 p.m. on September 26, 2018.

### **ACTIONS TAKEN BY THE BOARD OF REGENTS:**

Approval of the May 8-9, 2018 Board Minutes

Approval of the September 15-16, 2020 Future Meeting Dates

Appendix A - Roster - Board of Regents

I certify that, to the best of my knowledge, the foregoing minutes are accurate and complete.

Patricia Flatley Brennan, RN, PhD  
Director, National Library of Medicine

Jill Taylor, Ph.D.  
Chair, NLM Board of Regents