

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL LIBRARY OF MEDICINE  
MINUTES OF THE BOARD OF REGENTS  
February 12-13, 2019**

The 180<sup>th</sup> meeting of the Board of Regents (BOR) was convened on February 12, 2019, 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 3:40 p.m., followed by a closed session until 4:00 p.m. On February 13, 2019, the meeting reopened from 9:00 a.m. to 11:45 a.m. The meeting adjourned at 11:45 a.m.

**MEMBERS PRESENT** [Appendix A]

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

**CONSULTANTS PRESENT**

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

**EX OFFICIO AND ALTERNATE MEMBERS PRESENT**

Col. Thomas Cantilina, United State Air Force  
Dr. Carolyn Clancy, Veterans Health Administration  
Col. Kent DeZee, United States Army  
Dr. James Deshler, National Science Foundation  
RADM Joan Hunter, Office of the Surgeon General, PHS  
Capt. Matthew Lim, United States Navy  
Dr. Mary Mazanec, Library of Congress  
Dr. Dale Smith, Uniformed Services University of the Health Sciences

**SPEAKERS AND INVITED GUESTS PRESENT**

Dr. Nils Gehlenborg, Harvard Medical School  
Dr. Helene Langevin, National Center for Complementary and Integrative Health, NIH  
Dr. Julie Segre, National Human Genome Research Institute, NIH

**MEMBERS OF THE PUBLIC PRESENT**

Ms. Carla Funk, Friends of the National Library of Medicine  
Ms. Jill James, National Agricultural Library  
Dr. Barbara Redman, New York University/FNLM

## **FEDERAL EMPLOYEES PRESENT**

Dr. Patricia Flatley Brennan, Director, NLM  
Mr. Jerry Sheehan, Deputy Director, NLM  
Ms. Stacey Arnesen, Division of Specialized Information Services, NLM  
Ms. Dianne Babski, Division of Library Operations, NLM  
Ms. Joyce Backus, Division of Library Operations, NLM  
Dr. Dennis Benson, Office of the Director, NLM  
Dr. Olivier Bodenreider, Office of the Director, NLM  
Ms. Hua Florence Chang, Division of Specialized Information Services, NLM  
Mr. Ivor D'Souza, Office of Computer and Communications Systems, NLM  
Mr. Todd Danielson, Office of Administration, NLM  
Dr. Kathel Dunn, Division of Library Operations, NLM  
Ms. Lisa Federer, Office of Strategic Initiatives, NLM  
Dr. Valerie Florance, Division of Extramural Programs, NLM  
Ms. Kathryn Funk, National Center for Biotechnology Information, NLM  
Dr. Dan Gerendasy, Office of Strategic Initiatives, NLM  
Mr. Daniel Hartinger, Office of the Director, NLM  
Ms. Christine Ireland, Division of Extramural Programs, NLM  
Ms. Janice Kelly, Division of Specialized Information Services, NLM  
Ms. Elizabeth Kittrie, Office of Strategic Initiatives, 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. Irene Liu, National Center for Complementary and Integrative Health, NIH  
Dr. Clement McDonald, Lister Hill Center, NLM  
Mr. David Nash, Office of the Director, NLM  
Ms. Jody Nurik, Office of Communications and Public Liaison, NLM  
Dr. James Ostell, National Center for Biotechnology Information, NLM  
Dr. Dina Paltoo, Office of the Director, NLM  
Ms. Amy Powers, Office of Administration, NLM  
Dr. Jeffrey Reznick, Division of Library of Operations, NLM  
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM  
Ms. Samantha Tempchin, Division of Extramural Programs, NLM  
Ms. Victoria Townsend, Division of Extramural Programs, NLM  
Dr. Alan Vanbiervliet, Division of Extramural Programs, NLM  
Dr. Rebecca Williams, National Center for Biotechnology Information, NLM  
Dr. Maryam Zaringhalam, Office the Director, NIH

## **I. CALL TO ORDER AND OPENING REMARKS**

*Jill Taylor, Ph.D., Chair, BOR*

*Patricia Flatley Brennan, RN, Ph.D., Director, NLM*

[See video 1, Feb. 12, 2019, 00:00:28]

Dr. Taylor opened the meeting. Dr. Brennan announced the sad news of the recent passing of Donald West King, M.D., NLM's former deputy director for research and education. Those present observed a moment of silence in Dr. King's memory.

## **II. REPORT FROM THE OFFICE OF THE SURGEON GENERAL**

*RADM Joan Hunter, RN, M.S.W., Commissioned Corps of the U.S. Public Health Service*  
[See video 1, Feb. 12, 2019, 00:01:42]

RADM Hunter described the priorities and status of Surgeon General Jerome Adams, M.D., M.P.H., and the U.S. Public Health Service Commissioned Corps. The BOR thanked RADM Hunter for her presentation.

## **III. SEPTEMBER 25-26, 2018 MINUTES AND FUTURE MEETINGS**

*Jill Taylor, Ph.D., Chair, BOR*  
[See video 1, Feb. 12, 2019, 00:28:32]

**Motion:** The BOR approved a motion to accept the minutes of the September 25–26, 2018, meeting. Dr. Taylor asked all BOR to add the upcoming BOR meeting dates to their calendars.

## **IV. REPORT FROM THE NLM DIRECTOR**

*Patricia Flatley Brennan, RN, Ph.D., Director, NLM*  
[See video 1, Feb. 12, 2019, 00:29:40]

Dr. Brennan described recent NLM activities, including assessments of customer satisfaction and the Common Data Elements Repository, launch of the DataScience@NLM training program, and evaluation of the Disaster Information Management Research Center. As part of strategic plan implementation, NLM is integrating five divisions into four. She also reported on NLM budget and personnel changes as well as her receipt in 2018 of the Morris F. Collen Award of Excellence from the American Medical Informatics Association. During the discussion, BOR members noted that a January 2019 special issue of the *American Journal of Public Health* focuses on scientific visioning for the National Institute on Minority Health and Health Disparities, and they requested more details on plans for redesigning the Building 38 rotunda.

## **V. WORKING GROUP BREAKOUTS**

[See video 1, Feb. 12, 2019, 01:00:22]

BOR members divided into four breakout groups. Group representatives summarized their discussions later in the meeting.

## **VI. CORE CURRICULUM FOR BIOMEDICAL DATA SCIENCES**

*Nils Gehlenborg, Ph.D., Harvard Medical School*  
[See video 2, Feb. 12, 2019, 00:02:06]

Dr. Gehlenborg described the process used by the Department of Biomedical Informatics at Harvard Medical School to develop a core curriculum for graduate biomedical data science education. He explained the justification for the core curriculum (including the rising demand for biomedical data science education), the results of a survey of existing curricula, and the core competencies covered in the curriculum.

BOR members discussed the advantages of offering biomedical data science training for undergraduate students. In Dr. Gehlenborg's view, this knowledge is more relevant to work as a

physician than some medical school prerequisites. Dr. Gehlenborg agreed that data science education is most useful for those beginning college, but graduate programs are needed for those who already have biomedicine expertise.

## **VII. REPORT FROM THE NATIONAL CENTER FOR COMPLEMENTARY AND INTEGRATIVE HEALTH**

*Helene Langevin, M.D., National Center for Complementary and Integrative Health (NCCIH)*

[See video 2, Feb. 12, 2019, 00:49:30]

Dr. Langevin described the uses of complementary and integrative treatments and offered examples of NCCIH research. Dr. Langevin also described her own research on stretching the thoracolumbar fascia to relieve chronic pain.

During the discussion, Dr. Langevin offered the following observations:

- Medicine tends to focus on disease and prevention, but not a return to health.
- Most complementary and integrative health outcomes studies focus on pain.
- Studying the mind and body from the perspectives of, for example, traditional Chinese medicine or certain Native American practices, can yield new types of hypotheses to test.

BOR comments after Dr. Langevin's presentation were as follows:

- The BOR suggested that the *All of Us* Research Program leaders consider collecting data on the use of complementary and integrative health practices. Dr. Clancy can play a role in this area.
- Dr. Clancy said that the Department of Veterans Affairs might be interested in cosponsoring pain management research with NCCIH.

## **VIII. CHANGING THE CULTURE OF SCIENCE TO MAXIMIZE TALENT AND END HARASSMENT**

*Julie Segre, Ph.D., National Human Genome Research Institute*

[See video 3, Feb. 12, 2019, 00:01:02]

Dr. Segre described the “leaky pipeline,” which refers to declines in gender diversity at every stage of the biomedical research career path, and the slow progress for female investigators at universities and NIH. NIH has policies governing personal relationships and harassment as well as a hotline and web-based form for reporting harassment and inappropriate conduct. An NIH Advisory Committee to the Director working group is exploring additional ways to combat sexual harassment in science through training, diffusion of hierarchical and dependent relationships between trainees and faculty, and improvements in transparency and accountability.

During the discussion, Dr. Segre clarified that NIH policies address harassment targeted to both specific genders and racial/ethnic minority groups. NIH cannot directly influence the culture at universities, but it can communicate its expectation that awardee institutions will have similar policies. NIH is also identifying ways to mandate training in culture change and ending sexual harassment for investigators at these institutions.

BOR members strongly supported actions NIH is taking to combat harassment and inappropriate conduct by employees and grantees. They identified the following considerations for the NIH working group:

- Prevent retaliation for reports of harassment or inappropriate conduct
- Improve civility, including between faculty members and staff and between junior and senior faculty members
- Partner with today's students
- Learn from the experiences of industry and academia

## **IX. EXTRAMURAL RESEARCH PROGRAM**

*Valerie Florance, Ph.D., Division of Extramural Programs (EP), NLM*

[See video 3, Feb. 12, 2019, 00:45:46]

### **2019 Operating Procedures**

Dr. Florance invited the BOR to reaffirm the proposed BOR operating procedures, which include updates to reflect current NIH grant policies. Among the proposed changes are the following additions:

- Where budget reductions in a specific grant amount to more than 25% of the requested direct costs, NLM staff will solicit revised specific aims and timeline from the awardee.
- Applications under consideration for funding which received codes of “unacceptable” in relation to human subjects or representation of gender and/or minorities and/or children, or were received from foreign institutions will be brought to the attention of the EP Subcommittee of the BOR.

In addition, NLM proposed the following revision:

- EP staff will report all administrative increases, e.g., approved administrative supplements, in excess of \$100,000 direct costs to the EP Subcommittee at the next available meeting.

**Motion:** The BOR approved a motion to affirm the 2019 operating procedures as presented in the appendix in the BOR meeting book and summarized above.

### **NIH Triennial Inclusion Report**

Dr. Florance explained that NIH reports data from every Institute and Center to Congress every 3 years on the inclusion of women and minorities in clinical studies. The BOR received a draft report, for inclusion in the NIH-wide report, on NLM's research portfolio, process for addressing reviewer concerns about inclusion, and role of program and grants officers in this process. The report showed that NLM did not fund any application that did not meet NIH standards, such as an application that says it does not have human subjects but does; does not complete the human subjects section; or does not provide an enrollment table.

**Motion:** The BOR passed a motion to approve NLM's triennial inclusion report covering FY 2016–2018 as documented in the appendices to the BOR book for this meeting.

## Concept Clearance

Dr. Florance described a proposal for concept clearance for an extramural research initiative that NLM plans to launch on state-of-the-art methods and approaches to address problems in large health datasets. The next step would be to publish a notice of specific interest in the NIH Guide to Grants and Contracts that invites applications on this topic under NLM's existing research grant announcement or through the NIH parent R01 announcement. The basic concept is that health datasets may have errors or missing data that could skew findings based on these data and on machine learning tools built using these data.

BOR members offered feedback on the proposed concept, including concerns that some computational approaches to mitigate bias could impede the identification of important differences among populations. The board also suggested revising the goal to "understanding the challenges of representation in large datasets and their usage" and broadening the focus to systematic errors.

Dr. Brennan agreed that better study designs are needed to increase the representation of certain populations in human data. However, NLM deals with vast amounts of nonhuman data that have bias resulting from many sources, including sparseness of the data sets and inappropriate applications of certain analytical methodologies, and methods are needed to measure and mitigate these dataset biases. The BOR noted that administrative datasets, including those containing electronic health record (EHR) data, do not follow the same process of systematically recruiting participants as research projects do; methods are needed for understanding the limitations of these types of data.

Dr. Brennan proposed that the NLM Extramural Programs office revise the concept based on the BOR's feedback and share the amended description with the EP Subcommittee. The BOR agreed that if the EP Subcommittee approves of the amended text, NLM should publish the proposed notice of specific interest in the NIH Guide. The BOR asked Dr. Brennan to determine whether it is possible to separate human and nonhuman datasets in the notice.

## X. CLOSED PORTION

The closed portion of the meeting took place from 4:11 p.m. to 4:30 p.m. on February 12, 2019.

## XI. BUILDING 38 RENOVATION PROJECT UPDATE

*Joyce E.B. Backus, Associate Director for Library Operations, NLM*  
[See video 1, Feb. 13, 2019, 00:00:33]

The upcoming renovation of Building 38 will convert much of the first floor, which is increasingly underused, into flexible public and office space, conference rooms, small-group huddle rooms, and informal gathering spaces for staff. The first of the three phases over 3 years will involve renovations to the current main reading room into staff space and meeting rooms..

During the discussion, the BOR indicated that bringing staff from leased space into the renovated Building 38 could save money. Furthermore, moving work groups to more open space could change the workplace culture.

## **XII. WORKING GROUP REPORTS AND DISCUSSION**

### **Research Frontiers**

*Eric Horvitz, M.D., Ph.D., Microsoft Research*

[See video 1, Feb. 13, 2019, 00:15:43]

The Research Frontiers breakout group discussed the development of audacious goals in response to the recommendations of the Blue Ribbon Panel that reviewed NLM's Intramural Research Program in 2018, as well as the types of grand challenges issued by the National Academy of Engineering in its 2017 report, *NAE Grand Challenges for Engineering*. The group identified the following goals that NLM could address through its intramural and extramural research portfolios:

- Support the transfer of data-based knowledge among health-care providers
- Address the President's executive order on American leadership in artificial intelligence
- Enhance the availability of training datasets for researchers
- Develop better methods for analyzing real-world data
- Develop a platform for gathering data (e.g., from EHRs), generating predictions, and sharing these predictions with health-care providers
- Improve translation of biomedical knowledge to clinical policy and practice
- Develop tools to translate genetic test results into guidance for clinicians and patients
- Create a centralized repository for patients to voluntarily store their health data
- Ensure access to data in the right format

During the discussion, BOR members made the following comments:

- Because much genomic testing in the United States is conducted by industry, it is challenging to incorporate these results into processes that can translate these findings into guidance. However, BOR members asserted that patients own their own data, and they can give permission to use these data for altruistic purposes, such as research.
- NLM should help remove some of the barriers to access to large datasets, especially datasets from local and national government agencies.
- Data is the fuel of artificial intelligence, but patient privacy must be protected when these data are harnessed. Encryption techniques and machine learning are becoming more important in health care.
- Use cases are needed to show how data (including on adverse reactions to therapeutics) can be shared among health care providers while protecting patient privacy.
- The Department of Defense provides a model of storing patient data in a centralized repository. The department is building data on adverse reactions into clinical decision support systems to make it easier for providers to do the right thing. Efforts are needed to leverage large government datasets more effectively.

## **Strategic Planning**

*Jane Blumenthal, M.S.L.S., University of Michigan*

[See video 1, Feb. 13, 2019, 00:40:54]

The Strategic Planning breakout group was pleased with the progress in implementing NLM's strategic plan. The breakout group approved of NLM's efforts to streamline its internal operations and to end or consolidate underused services. The breakout group emphasized the importance of training in health information resources and expanding access to the library's resources.

Dr. Brennan said that a helpful part of this breakout group meeting was the discussion of how staff are likely to respond to changes and strategies to help staff find meaning and satisfaction in their work as it changes in response to new activities and renovations at NLM.

BOR members offered the following suggestions to help staff adapt to changes:

- Organize frequent, brief, all-hands huddles
- Pay attention to changes in staff communication patterns
- Inform staff at the beginning that changes will continue
- Share talking points with supervisors for discussions with staff about changes
- Think about conducting information evaluations or organizational network analyses of communication patterns
- Use stories to share the experiences of staff whose efforts support the new culture

## **Collections**

*Dale Smith, Ph.D., Uniformed Services University of the Health Sciences*

[See video 1, Feb. 13, 2019, 01:00:07]

The Collections breakout group agreed that the primary purpose of the library's collections activity is for access, although preservation and serving as the library of record for science-guided health care in the United States are also part of NLM's mission. The group discussed the need to include health care approaches that are not traditional or are not widely used in the United States, such as chiropractic medicine, in the library's collections. Other discussion topics were the relationship between the library's new data science mission and its collections policy and how to decide what to preserve (e.g., data only or both data and the codes used to manipulate data).

In a recent editorial in the *Journal of the American Medical Informatics Association* (2019;26:185-187) on transparency, reproducibility, and replicability, Dr. Bakken encouraged the journal's authors to deposit their data, including their code, in the Dryad Digital Repository.

BOR members made the following comments:

- According to some BOR members, no library, including NLM, can be the library of record for biomedical data because of capacity and other resource limitations. BOR members offered the following perspectives on this issue:
  - NLM might determine which data to conserve for the public good and for the record, and which data to conserve for a specified period before replacing these data.



- NLM could send different datasets to different repositories; NLM would then be a leader in creating international specifications for data to ensure scientific reproducibility.
- The inability to store all biomedical data is a storage problem, and NLM should consult engineers on how to expand storage capacity.
- However, BOR members acknowledged that even with unlimited resources, NLM could not store all biomedical data.
- Therefore, NLM's role in coordinating the storage of data and code needs to be clarified.
- A more important issue than how much data to collect and store is how to provide access to the data that are collected.
- NLM needs to explore ways to convert data into executable findings.

### **Public Service**

*COL Kent DeZee, United States Army*

[See video 1, Feb. 13, 2019, 01:22:26]

The Public Service breakout group reviewed and endorsed the activities of NLM's National Network Coordinating Office (NNCO) and the NLM portfolio assessment process showing alignment between NLM activities and the library's mandate and mission. The breakout group also offered the following recommendations for NLM:

- Break down silos among the public service components of NLM
- Enhance partnerships with other federal agencies
- Reach out to refugees and veterans
- Combat the spread of misinformation in the age of social media

Dr. Brennan said that NLM must protect against the spread of misinformation by social media and help the public identify and use authoritative information.

BOR comments were as follows:

- Most NLM outreach programs are designed for researchers, followed by clinicians and then the lay public. NLM has opportunities to enhance intersections among these groups, including through use of digital technologies.
- The International Telecommunication Union has a Focus Group on AI for Health created in collaboration with the World Health Organization, that might be a good partner for NLM.

Action items were as follows:

Dr. Bakken will send information on AI for Health to Drs. Taylor and Clement McDonald.

### **XIII. SPECIALIZED INFORMATION SERVICES (SIS) UPDATE**

*Hua Florence Chang, M.S., SIS, NLM*

[See video 2, Feb. 13, 2019, 00:01:09]

Ms. Chang reviewed the history of SIS, established in 1967, as well as SIS services and accomplishments. In response to the 2017–2027 NLM strategic plan, most SIS components will

be merged into Library Operations in 2019, and the SIS technical group will be integrated into the Office of Computer and Communications. Whether to continue, sunset, or integrate key SIS products and services into other NLM products and services is under review.

The BOR said that SIS has done great work and offered the following comments and suggestions for NLM to consider:

- SIS has done wonderful work on HIV and exemplifies how NLM can develop similar offerings for other diseases that affect underserved populations.
- NLM has an important role as an authoritative resource on toxicology, emergency management, and environmental risks in underserved populations.
- When NLM plans to surrender custodianship of certain pieces of information, the History of Medicine Division at NLM might be consulted on what should be preserved.
- It would be valuable for any information that NLM stops collecting, especially toxicologic and environmental materials, to continue to be available in some form (e.g., from other NIH Institutes and Centers, other national libraries, or the National Archives).
- An emerging topic of interest relates to the effect of climate on the relationship between gene-environment interactions and health.

#### **XIV. APPOINTMENT OF NOMINATING COMMITTEE FOR BOR CHAIR**

Drs. Carolyn Clancy, Mary Mazanec, and Dale Smith agreed to serve on the nominating committee for the next BOR chair. They will review eligible candidates and report to the BOR at the May 2019 meeting.

#### **XV. ADJOURNMENT**

Dr. Taylor adjourned the Board of Regents meeting at 11:45 a.m. on February 13, 2019.

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

Approval of the September 25-26, 2018 Board Minutes

Approval of the February 9-10, 2021 Future Meeting Dates

Approval of the Revised Grant Operating Procedures and Inclusion Report on Women and Minorities

En Bloc Approval of Primary and Dual Grants Assigned to NLM

Appointment of Nominating Committee for Next BOR Chair

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