

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL LIBRARY OF MEDICINE**

**MINUTES OF THE BOARD OF REGENTS  
September 14-15, 2010**

The 155<sup>th</sup> meeting of the Board of Regents was convened on September 14-15, 2010, at 9:00 a.m. in the Board 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 3:30 p.m., followed by a closed session for consideration of grant applications until 4:00 p.m. On September 15, the meeting was reopened to the public from 9:00 a.m. until adjournment at 12:00 p.m.

**MEMBERS PRESENT** [Appendix A]:

Mr. Bruce James [Chair], Nevada New-Tech, Inc.  
Dr. John Connolly, University of California, Irvine  
Dr. Carol Friedman, Columbia University  
Dr. Joyce Mitchell, University of Utah  
Dr. Louis Rossiter, The College of William and Mary  
Ms. Virginia Tanji, University of Hawaii at Manoa

**EX OFFICIO AND ALTERNATE MEMBERS PRESENT:**

Dr. Michael Corriere, U.S. Department of the Navy  
Ms. Eleanor Frierson, U.S. Department of Agriculture  
Dr. Byron Hepburn, United States Air Force  
Ms. Caryl Kazen, Veterans Health Administration  
Ms. Kathryn Mendenhall, Library of Congress  
Lt. Col. Todd Poindexter, United States Air Force  
Dr. Charles Rice, Uniformed Services University of the Health Sciences  
RADM David Rutstein, Office of the Surgeon General, PHS  
Dr. Howard Wactlar, National Science Foundation  
Col. Jay Zarate, United States Air Force

**CONSULTANTS TO THE BOR PRESENT:**

Dr. Tenley Albright, Massachusetts Institute of Technology  
Dr. Holly Buchanan, University of New Mexico  
Dr. H. Kenneth Walker, Emory University School of Medicine

**SPEAKERS AND INVITED GUESTS PRESENT:**

Dr. Marin Allen, Office of Communications, Office of the Director, NIH  
Dr. Loren Cobb, University of Colorado, Denver  
Dr. Simon Ndira, HealthNest  
Dr. Alan Waxman, American Society for Colposcopy and Cervical Pathology  
Dr. Nicolas Wentzensen, National Cancer Institute, NIH

**MEMBERS OF THE PUBLIC PRESENT:**

Ms. Helen Harley, Friends of the National Library of Medicine  
Mrs. Mary Lindberg, Public  
Mr. Thomas West, Kransow Institute

**FEDERAL EMPLOYEES PRESENT:**

## September 14-15, 2010 - Board of Regents

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Dr. Donald A.B. Lindberg, Director, NLM  
Ms. Betsy Humphreys, Deputy Director, NLM  
Dr. Milton Corn, Deputy Director for Research and Education, NLM  
Dr. Michael Ackerman, Lister Hill Center, NLM  
Ms. Stacey Arnesen, Division of Specialized Information Services, NLM  
Ms. Joyce Backus, Division of Library Operations, NLM  
Ms. Kathy Cravedi, Office of Communications and Public Liaison, NLM  
Ms. Celeste Dade-Vinson, Office of the Director, NLM  
Mr. Todd Danielson, Office of the Director, NLM  
Ms. Josseline de Saint Just, Division of Extramural Programs, NLM  
Mr. Ivor D'Souza, Office of Computers and Communication Systems, NLM  
Ms. Kathel Dunn, Division of Library Operations, NLM  
Ms. Gale Dutcher, Division of Specialized Information Services, NLM  
Ms. Martha Fishel, Division of Library Operations, NLM  
Dr. Valerie Florance, Division of Extramural Programs, NLM  
Dr. Kin Wah Fung, Lister Hill Center, NLM  
Mr. Payel Ghosh, Lister Hill Center, NLM  
Ms. Jeanne Goshorn, Division of Specialized Information Services, NLM  
Ms. Kristen Greenland, Office of the Director, NLM  
Mr. David Hale, Division of Specialized Information Services, NLM  
Dr. Sally Howe, Lister Hill Center, NLM  
Dr. Zoe Huang, Division of Extramural Programs, NLM  
Ms. Christine Ireland, Division of Extramural Programs, NLM  
Mr. Sheldon Kotzin, Division of Library Operations, NLM  
Ms. Lisa Lang, Lister Hill Center, NLM  
Dr. David Lipman, National Center for Biotechnology Information, NLM  
Dr. Robert Logan, Office of Communications & Public Liaison, NLM  
Mr. L. Rodney Long, Lister Hill Center, NLM  
Ms. Becky Lyon, Division of Library Operations, NLM  
Ms. Wei Ma, Lister Hill Center, NLM  
Dr. Clement McDonald, Lister Hill Center, NLM  
Ms. Melanie Modlin, Office of Communications & Public Liaison, NLM  
Mr. David Nash, Office of the Director, NLM  
Dr. Aaron Navarro, Lister Hill Center, NLM  
Ms. Alison Oppenheim, Office of Health Information Program Development, NLM  
Ms. Shana Potash, Lister Hill Center, NLM  
Dr. Arthur Petrosian, Division of Extramural Programs, NLM  
Dr. Steven Phillips, Division of Specialized Information Services, NLM  
Dr. Barbara Rapp, Office of Health Information Program Development, NLM  
Dr. Jeffrey Reznick, Division of Library Operations, NLM  
Ms. Julia Royall, Office of Health Information Program Development, NLM

## **September 14-15, 2010 - Board of Regents**

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Dr. Angela Ruffin, Division of Library Operations, NLM  
Mr. Jerry Sheehan, Office of the Director, NLM  
Dr. Elliot Siegel, Office of Health Information Program Development, NLM  
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM  
Ms. Jennifer Sticco, Office of the Director, NLM  
Dr. Paul Theerman, Division of Library Operations, NLM  
Dr. George Thoma, Lister Hill Center, NLM  
Dr. Alan Vanbiervliet, Division of Extramural Programs, NLM  
Dr. Fred Wood, Office of Health Information Program Development, NLM  
Dr. Jane Ye, Division of Extramural Programs, NLM  
Dr. Deborah Zarin, Lister Hill Center, NLM

### **I. OPENING REMARKS**

Mr. Bruce James, Chairman of the NLM Board of Regents, welcomed the Regents, alternates, and guests to the 155<sup>th</sup> meeting of the NLM Board of Regents.

### **II. REPORT FROM THE OFFICE OF COMMUNICATIONS, OD/NIH**

Dr. Marin Allen, Deputy Associate Director of the NIH Office of Communications and Public Liaison (OCPL), discussed public communication at NIH.

Dr. Allen described NIH OCPL as a source, hub/connector, and resource for the 27 institutes and centers that make up NIH. The office functions include: director's communications; media relations; public information; freedom of information; special events/NIH visitors center; internal communications; online information; editorial operations; and public and community liaison. The office coordinates across NIH, across other US government agencies and departments, and with constituency groups. It creates health messages and educational campaigns to improve public health; engages the public; and engages the media. Dr. Allen said the most important functions are probably strategic communication planning and working across the institutes and centers. The audiences include the President and Congress; patients and advocacy groups; scientists and health care professionals; professional societies and industry. Dr. Allen gave a quick snapshot of NIH: roughly 36,000 employees and contractors in all locations; NIH research serves some 3,000 institutions in all 50 states, territories and more than 90 countries; NIH supports 325,000 scientists and scientific staff through grants with a budget of \$32 billion plus \$10 billion in American Recovery and Reinvestment Act (ARRA) funding.

Dr. Allen said the office has learned it needs to communicate smarter, faster, more often, and to make sure information is branded as NIH. The communication goals are to help the public understand: the benefits of investing in biomedical research; the role research plays in transforming medicine in the 21<sup>st</sup> century; the public and private sector compact to advance biomedical discovery; and the connection between NIH and the nation's research community. The communication approach is to draw a clear connection between discovery and health and to do it by telling real stories about real people-- both patients and scientists. Recent "incoming" issues include questions about animals in research, stem cells, scientific integrity. NIH OCPL is involved in social media, selectively matching the media to the message. The office also is working to improve outreach to NIH grantees and the public information officers at the grantee institutions. The NIH homepage is being revamped. The new version will be more

## **September 14-15, 2010 - Board of Regents**

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interactive and will have more visualization to help people understand the science process. Dr. Allen also noted areas where NIH and NLM collaborate: *NIH MedlinePlus* magazine; tagging vetted resources; evaluation efforts; presentation to the network of grantee institution public information officers.

In the discussion after the presentation, Board Chairman James said he wants to make sure the communication efforts of NIH and NLM don't conflict but complement each other. Dr. Allen noted that the communication directors of all NIH institutes meet regularly and work together not in parallel.

Dr. Joyce Mitchell asked how NIH evaluates its communications efforts. Dr. Allen said they are focusing on user accessibility and satisfaction. They put out a request for information to ask the public how they wanted their information delivered and are now analyzing the data.

NLM Director Dr. Donald A.B. Lindberg noted the success of *NIH MedlinePlus* magazine and called it a good example of the Institutes, NLM and the Friends of NLM working together effectively. He said the magazine needs another \$3 million dollars a year in funding to produce another 4 million issues to make it a significant publication. He said NLM is delighted to support the magazine to the greatest possible extent but thinks the magazine ought to be funded if not by individual institutes then by NIH central funds.

### **III. REPORT FROM THE OFFICE OF THE SURGEON GENERAL, PHS**

Rear Admiral David Rutstein presented the report from the Office of the Surgeon General (OSG). The Patient Protection and Affordable Care Act (PPACA) that was signed into law in March created a new Public Health Sciences Track to be administered under the Surgeon General. The measure provides scholarships to 850 students in exchange for serving in the public health service and allows for the hiring of faculty at institutions around the country. A working group has been formed to flesh out the details, but funding hasn't been identified. The law states the funding would come from the Public Health and Social Services Emergency Fund, but that money is already spoken for. The program won't get underway until Congress gives some clearer guidance on funding.

Dr. Rutstein provided an update on the National Prevention, Health Promotion and Public Health Council, which the Surgeon General chairs. Also established by the PPACA, it includes 12 Cabinet-level secretaries, plus other people the Surgeon General identifies. The council is charged with coming up with a national prevention strategy by March of next year. A work group of designees identified by the Cabinet secretaries is assisting by drafting a proposed framework for the strategy and a plan for getting input from a wide range of stakeholders. It's the first time in the history of the Office of the Surgeon General that prevention is a priority, written in a statute and backed up by a \$15 billion dollar national prevention trust fund. The law also establishes a 25-member advisory group, which will give the council input from a variety of private sector entities.

### **IV. MAY 2010 MINUTES AND FUTURE MEETINGS**

Chairman James introduced new ex-officio member Howard Wactlar, Division Director for Information Intelligence Systems at the National Science Foundation. Chairman James also introduced the ex-officio representatives sitting in for the U.S. Air Force, Lt. Col. Todd Poindexter, and for the Veterans Health Administration, Ms. Caryl Kazen.

## **September 14-15, 2010 - Board of Regents**

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The Regents approved without change the minutes from the May 11-12, 2010 meeting. Dates for the February and May 2011 meetings already have been agreed upon. The fall 2011 meeting was set for October 4-5 to coincide with the opening of the new exhibition.

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

NLM Director Donald A.B. Lindberg began his report with the FY 2011 budget, saying there basically isn't one because Congress hasn't passed it. NLM is expecting the new fiscal year to start under a Continuing Resolution.

Dr. Lindberg announced the retirement of Dr. Elliot Siegel, Associate Director for Health Information Programs Development, and the appointment of Deborah Ozga as the new Head of the Index Section. Kathel Dunn introduced the 2010-2011 NLM Associate Fellows. New staff members from the Lister Hill National Center for Biomedical Communications and the National Center for Biotechnology Information also were introduced.

Dr. Lindberg updated the Board on several legislative and regulatory matters. The PPACA, previously mentioned by Dr. Rutstein, contains money to develop a Comparative Effectiveness Research (CER) Inventory that would be accessible to the public through a web-based system. NLM is on the HHS Advisory Committee for the inventory initiative. With regard to Health IT, HHS issued three rules related to meaningful use of electronic health records. Two of the rules are of particular interest to NLM. One identifies a set of standards and implementation guides required for use in certified electronic health record (EHR) products, including three standards that NLM supports or develops: SNOMED CT, LOINC and RxNORM. Another rule gives doctors' offices and hospitals a menu of objectives to achieve in order to demonstrate "meaningful use" of EHRs and qualify for incentive payments. One requirement that doctors can choose to meet is the use of electronic health record technology to identify education resources for their patients. NLM's new MedlinePlus Connect feature is one mechanism for meeting this requirement. NCBI Director Dr. David Lipman recently testified on the NIH experience at a congressional hearing on public access policies practices. The House passed the Federal Advisory Committee Act that requires agencies to disclose information on the charter and makeup of their advisory committees.

Dr. Lindberg praised Dr. Deborah Zarin of the Lister Hill National Center for Biomedical Communications (LHNCBC) and her predecessor Dr. Alexa McCray, as ClinicalTrials.gov marks its tenth anniversary. As of August 2010, the registry contained almost 94,000 studies and 2,100 results records. Dr. Zarin gave the Board a quick update. She noted over the past 10 years there has been a huge culture shift in terms of trial registration. Now, it's rare to find a trial that isn't registered. In terms of summary results data, there has not yet been a culture shift. There's no ingrained assumption that results will have to be submitted to ClinicalTrials.gov, but that will come. Dr. Lindberg noted it's also the 10<sup>th</sup> anniversary of PubMed Central, which now contains about to 2 million articles.

Dr. Lindberg informed the Board about several noteworthy events. In November, NLM is hosting the first conference for users of its Journal Archiving and Interchange Tag Suite, now a de facto standard for electronic journals in all disciplines. Also in November, NLM's History of Medicine Division will participate in an NIH symposium marking the centennial of James B. Herrick's article presenting the first description of sickle cell disease in Western medical literature. The 2010 NLM Informatics Training

## **September 14-15, 2010 - Board of Regents**

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Conference was held in Denver in June. Nearly 380 people from all 18 current NLM training programs participated. The new NLM exhibition on Native American concepts of health and illness opens in the fall of 2011. The exhibition will focus on American Indians, Alaska Natives and Native Hawaiians.

Dr. Lindberg also reported that NLM is using ARRA funds to update the Insight Toolkit (ITK) image analysis software, which is widely used in imaging research and product development. ITK version 4.0 will take advantage of emerging computer hardware resources.

### **VI. TEACHING COLPOSCOPY: LHC COLLABORATION WITH NCI AND THE AMERICAN SOCIETY FOR COLPOSCOPY AND CERVICAL PATHOLOGY**

NLM, in collaboration with the National Cancer Institute (NCI) and the American Society of Colposcopy and Cervical Pathology (ASCCP), has developed software called the Teaching Tool—an online, image-based testing system-- to assess the knowledge and expertise of medical professionals in the field of colposcopy, which is a critical step in cervical cancer screening. After a woman has an abnormal Pap test, a health care provider looks at the cervix with a colposcope (which may be thought of as a medium-powered microscope), identifies the area most likely responsible for the abnormal Pap, and then takes a biopsy.

Rodney Long, an engineer in the Lister Hill National Center for Biomedical Communications (LHNCBC) gave an overview of the Teaching Tool software application. With this software, test takers are shown an image of the cervix along with a corresponding question, and then responses are collected and scored. Long called the Teaching Tool a success story because it has moved from the lab to real world use. The ASCCP is currently using the Teaching Tool to give two professional proficiency exams. The Teaching Tool has a database of 500 questions organized into 16 categories called question “pools.” The exams are created dynamically. When a user requests to take an exam, the questions are pulled randomly from the 16 question pools. Data and images for the exams come from two NCI multi-year studies of cervix pre-cancer.

Nearly 50 residency programs are using the Teaching Tool, including George Washington University, Baylor College of Medicine, and the University of Toronto. The Teaching Tool also produces user performance reports. The reports can help test takers identify their strengths and weaknesses and can help the people who design the training programs target areas for improvement.

Dr. Nicolas Wentzensen discussed how NCI is using NLM tools in its Biopsy Study, which seeks to answer a number of questions such as: What is the benefit of taking multiple biopsies? How much more disease will be found? How are multiple lesions on the cervix related? For the study, NCI is using a tool NLM developed that enables health care providers to mark boundaries on the image of the cervix—to outline the lesions. The image seen during the colposcopy is transmitted to a laptop computer equipped with NLM’s Boundary Marking Tool (BMT). The clinician uses the BMT to outline the lesions and record his/her impression of what was seen during the colposcopy. The annotations done at the clinic are then compared with external reviews from experts. The study started at the University of Oklahoma and is being expanded to sites in other parts of the world. The goal is to create a large database of images with annotations and outcomes from different regions with different screening programs.

Dr. Alan Waxman of the ASCCP said his group currently uses the Teaching Tool to assess colposcopists in training and will also use it to assess more experienced colposcopists. Dr. Waxman said the ASCCP

## **September 14-15, 2010 - Board of Regents**

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previously had difficulty in developing a valid assessment exam. The centerpiece of the exam is the case presentation question. A scenario is presented, an image of the cervix is shown, and then test takers are asked where they'd take the biopsy, what they think it will show, and how they will manage the patient. Dr. Waxman said the challenge had been obtaining high-quality, unambiguous, validated photos of the cervix; creating validated lesion location questions; and developing interactive capability. The collaboration with NLM and NCI enabled ASCCP to create a new and better test that has been online since mid-May.

In questions following the presentation, consultant Dr. Kenneth Walker commented that this system seems ideal for underserved areas where people may not be well trained. Dr. Waxman said there are places in the world where people are doing telecolposcopies, and this would be perfect for that. Dr. Tenley Albright applauded the Teaching Tool as another NLM innovation. She noted one reason this is so important is that if cervical cancer is found earlier, only a small section of the cervix has to be removed so a woman can go on to have children.

### **VII. PRESENTATION OF REGENTS AWARD**

Chairman James presented the 2010 NLM Board of Regents Award to Dr. Alejandro Schäffer, a staff scientist at the National Center for Biotechnology Information. He was cited for "exceptional achievement in applying bioinformatics research tools to the understanding and treatment of human genetic diseases."

### **VIII. USING DIGITAL PENS FOR MALARIA RESEARCH IN UGANDA**

NLM Chief of International programs, Ms. Julia Royall, explained how a team from NLM, a group of students and a community in Africa came together to improve health care. She introduced participants Wei Ma, chief of NLM's Application Branch, OCCS, and Dr. Simon Ndira from Uganda. She provided a brief review of NLM's previous and ongoing work with African malaria researchers, medical librarians, medical journal editors, and medical students. Ms. Royall discussed how NLM, with modest funding, transferred a digital pen application developed as part of NLM's disaster preparedness research activities, to serve an observational study of actual bednet use in Uganda. The project sought to determine whether the 300 bednets distributed in 2006 were actually being used in Mifumi village to prevent malaria and whether digital pen technology could support efficient and timely collection, collation, and presentation of the research data. A digital pen and paper was brought to Uganda and medical students were then trained to use it in March. They conducted their study in April. In May and June, they analyzed the data and wrote a report in conjunction with Dr. Ndira and his team.

Ms. Ma explained that the digital pen features Bluetooth, a battery, memory, ink, a processor and a camera. The digital pen works together with the digital paper and can uniquely identify the position of the pen that coordinates with the paper. It collects and transmits patient data. Mr. Ndira explained that data collected with digital pen can be uploaded to a digital database, hard and soft copies produced, and results quickly analyzed. He believes such information technology is useful especially in remote settings like Mifumi.

Mr. Ndira formed teams of researchers. In March of this year, a workshop was held with community medical students to develop a questionnaire using the digital pen for data collection. The students were

## **September 14-15, 2010 - Board of Regents**

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trained to use the digital pen and how to store and process the data. They were also taught to retrieve the data and use a Web-based application. Armed with the digital pen, the medical students surveyed 170 households in Mifumi late at night, over a period of 10 days. The community was informed about the study and consented to participate, but did not know exactly when the survey would occur.

The researchers learned that the majority of households used the mosquito nets. In nearly all the households, the nets in use were being shared by family members, with priority given to adults in some households. In most households, the nets were hung appropriately. Where the nets were not used appropriately, the contributing factors were limited space and lack of knowledge. In only 74 households were mosquito nets put in place before dusk, the time of day when the female anopheles mosquito begins searching for her blood meal. This timing problem apparently contributes to the belief by some Ugandans that, even when mosquito nets are used, people may contract malaria. The study team reported the results to more than 150 community residents in July. The digital pen technology proved an effective way to conduct and foster research.

Board members asked whether bednets are hard to come by. The presenters responded no, but there is still a lot of confusion about how they should be used. For example, you can't cover a window but leave other entrances open for mosquitoes to gain entrance to the home. The rate of malaria is high and, sadly, the disease usually claims the lives of children under age five, but morbidity and mortality are declining

Asked where money for the nets comes from, the panel responded that it comes from different organizations, including the government. Nets are distributed to mothers and children free of charge throughout Africa to reduce mortality. Dr. Lindberg observed that there are competing strategies for combating malaria, which is discouraging.

Dr. Walker gave a quick review of the evolution of writing instruments, beginning in 4000 BC, when bones were used to write on moist clay. In recent years there has been an explosion in the use of digital pens. In rural Ghana they are used to open bank accounts. It is clear that digital pens are a suitable form of writing and give people with limited resources enhanced ability to do their own research. Dr. Walker observed that perhaps methods used in NLM's work in Uganda could be applied to US efforts to reduce childhood obesity.

## **IX. IMPROVED TRACKING FOR EMERGING DISEASES FROM CLIMATE CHANGE**

Dr. Loren Cobb is with the Department of Mathematics and Statistical Science at the University of Colorado in Denver. He explained that emerging diseases include all sorts of epidemics that might occur in the future. Climate change, he noted, is warming the globe, the tropics and the arctic regions. He said that our disease structures and the patterns of disease are changing and new diseases are emerging. He received NLM ARRA funding to bring mathematics to bear on this problem. He explained that his specialty is making dynamic mathematical models of societies in terrible trouble. He works worldwide on these models. First, he noted that both wildfires and epidemics share the same dynamics. There is a phrase that we use, that a disease is moving like wildfire through a population. He got together with the wildfire folks and the people who work in the area of atmospheric research to bring attention to the epidemic tracking problem and methods that have been radically successful, revolutionary over the last 10 years, in meteorology and wildfires. His department has pioneered advanced mathematics on the morphing ensemble common filter. It is used to track wildfires and weather systems and has made



weather tracking a completely different field than it was 15 years ago. He believes that tracking an epidemic, or in fact any dynamic spatial process, with aggregated data, sparse data and error-prone data is best accomplished with these robust methods, known collectively as data assimilation. To demonstrate, Dr. Cobb showed a simulation of a wildfire. He explained that this was done at the National Center for Atmospheric Research on a supercomputer. In the standard epidemiological literature, systems are defined by three variables: 1) the population that can be harmed by an epidemic, which corresponds to fuel that has not yet been reached by a wildfire; 2) the infected group of people who correspond to the fuel that is being combusted in a wildfire; and 3) the removed population—the people who are either dead, recovered and immune or quarantined, and they correspond to completely burned fuel. His group proposed to bring the methodology applied to wildfires and weather tracking into epidemiology. As a test, he reconstructed the Black Death epidemic of 1346. What did it look like spatially? He described the underlying model they used for the test and to drive their tracking system. He uses what is called Bayesian Data Assimilation. He explained that you don't just go out and gather data and then analyze it. Data is constantly arriving and every time a new observation arrives, which might be a report from a clinic or a hospital, they weigh the reliability of the incoming data and adjust the position. The model assumes that the data are going to be sparse, filled with errors, patchy and aggregated. But it still works. They have run exercises with ministries of health for major pandemics like smallpox or bird flu. They have shown that this new tracking method along with this simulation actually copes very well even with the toughest case. If the data get worse, the prediction gets fuzzier. The scary situation they are facing is that some diseases will have no vaccine or cure and this is becoming more apparent with the warming of the Earth, which is moving diseases into areas where they never were before. Another problem is the growing contact between human beings and animals. In several areas of the world, diseases, usually viral, have a much greater chance of hopping from the animal system to humans, as occurred with AIDS and Ebola. It may be behind the recent hemorrhagic disease in the Congo. This is more than just data collection. It is developing an image of society as a whole and the health of populations. This can be used for infant mortality, for refugee flows, migration, poverty, behavioral syndromes, alcoholism, domestic abuse, etc. It might be something that in the future that would be suitable as a wide model of public health. He explained that NLM's ARRA funds have allowed him to expand the scope of his research — helping to determine which diseases will arise and where and how they will move through the population and what we can do about them.

Asked whether he expected his research would lead to preventive measures, Dr. Cobb responded affirmatively, noting that it could help to determine when to quarantine, where to apply vaccines, and when to evacuate areas and use isolation strategies—all the common tools of epidemiology strategy. He said that refugee camps and wildfires sparked the idea of mapping the spread of diseases. Weather distinguishes between predictions and forecasts. A forecast says “if the trends continue like they are now then over the next few days or weeks, here is what we will see.” A prediction is far more concrete. We would like to make predictions, Dr. Cobb noted in closing, but, mostly, what you see here is just forecasting.

## **X. EXTRAMURAL PROGRAMS REPORT**

Mr. Bruce James resumed the meeting by mentioning that Dr. Lindberg had an unexpected announcement to make. The NLM Director said that President Obama had given the Presidential rank award to Betsy Humphreys. The group applauded enthusiastically. Next, Mr. James introduced Dr. Valerie Florance.

## **September 14-15, 2010 - Board of Regents**

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Dr. Florance explained that she wanted to give BOR members a thematic view of the research NLM funds in its grant programs, and the way ARRA funds affected those investment areas. She used two data sets - research grants awarded in 2007 and 2008 using appropriations funds (i.e., before ARRA), and research grants funded in 2009 and 2010, using both appropriations and ARRA funds. She began with goals from the Library's Long Range Plan, showing grant investments in the three long-range plan goals related to research: (1) access to knowledge; (2) users and communication; and (3) promoting discovery. She then introduced seven portfolio areas which crosscut those goals and provide a more functional view of the extramural research investments. Those areas are: basic informatics, basic bioinformatics, translational informatics, clinical informatics/electronic health record, public health informatics, user-centered sciences, and scientific communication. She then presented tables showing the number of projects awarded in each goal or functional area. The point was made that ARRA funds helped the Library shift emphasis, e.g., from bioinformatics toward translational, or increase investment in a desired area, such as public health informatics and user sciences. She characterized her approach as a conceptual map of NLM's extramural research investment.

Dr. Florance continued by presenting examples of specific areas of investment, using the NIH RePORTER system that is available to the public. Although NLM's extramural grants budget is small, NLM figures in the NIH Top 10 for the number of projects awarded in areas such as "electronic health records," "health information" and "information retrieval." These views also show other NIH Institutes and Centers' funding in the same areas, supporting future collaborations and also giving informatics researchers a view of alternate sources of grant support.

Mr. James then asked about the percentage of the grant budget going into the various areas, and whether Extramural Programs had targets for spending on particular topics. He also noted that while information of this type, which focuses on inputs, is important, it would be helpful to hear about the outputs - what are people accomplishing with the funds. Dr. Florance replied that EP staff have been working on strategies for tracking the outputs and measuring the impact of funded research. Several pilot studies have been done looking at metrics such as impact factors, but these are based only on articles. NLM's funded researchers also produced patents, software and knowledge resources, so a method is needed for taking those into account as well. Mr. James thanked Dr. Florance for the presentation and encouraged her to continue bringing information of this kind to the Board, so its members can decide how best to assist the Library in its goals.

## **XI. NLM'S SUPPORT FOR MEANINGFUL USE OF ELECTRONIC HEALTH RECORDS**

Ms. Betsy Humphreys began by noting that NLM activities relating to HHS initiatives to promote "meaningful use" of electronic health records are in line with objectives in the NLM 2006-2016 Long Range Plan. The plan states that "NLM must continue to enhance [its health data standards] efforts in response to specific US government priorities" and adjust its priorities accordingly. To this end, the Board established a working group whose report which was accepted by the full Board in May 2009, just a few months after the American Recovery and Reinvestment Act (ARRA) with its major health information technology revisions. Among many other things, ARRA establishes and funds incentives for Medicare and Medicaid providers to implement and demonstrate "meaningful use" of "certified" electronic health record products. The incentives begin in 2011 and non-use penalties will begin for some provider segments in 2016. Several rules have recently been published to implement these provisions. Key players include: the Centers for Medicare and Medicaid Services (CMS), which issued a rule

## September 14-15, 2010 - Board of Regents

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defining eligibility, payment procedures and phase 1 “meaningful use” criteria; the Office of the National Coordinator for Health Information Technology (ONC), which issued rules defining the standards, implementation specifications and criteria for certification of EHR products and the process for certifying the products; and the National Institute of Standards and Technology (NIST), which will publish the test procedures to be used in interim certification of EHRs. Ms. Humphreys then reviewed the basics of meaningful use. There are slightly different criteria for eligible health care professionals and eligible hospitals, and also for Medicare and Medicaid providers. The requirements for meaningful use are intended to increase over time, with initial criteria in 2011 and more stringent criteria in 2013 and 2015. There are “core” criteria that are mandatory and also “menu” criteria, allowing providers to select the requirements they won’t meet; up to five may be deferred. Requirements address multiple areas: data capture; exchange of patient data between providers; provision of data and educational information to patients, reporting quality measures to CMS; and privacy and security protections. Providers must use health data standards to meet some criteria.

Ms. Humphreys provided examples of how the “meaningful use” criteria that health professionals and hospitals must meet dovetail with the criteria for certified EHR products, which must be used to obtain incentive payments. NLM’s MedlinePlus Connect feature would be one way that an EHR could meet the certification requirement to be able to provide patient-specific education information related to problems, tests, and medications in the patient’s electronic record. The ONC is very interested in MedlinePlus Connect as a free source of information that can be used by EHR developers to meet this criterion. .

Another example dealt with the requirement to maintain an active medication list. EHRs must support the use of a vocabulary included in RxNorm in the patient’s medication list. Essentially, the 2011 meaningful use criteria promote the use of three NLM-supported vocabulary standards: LOINC (Logical Observation Identifier Names and Codes) for lab test results; RxNorm, for medications; and SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) as one of two options for problems.

Providers must have a UMLS license to use RxNorm and SNOMED CT. Not surprisingly, NLM has seen increased registration for licenses as a result of meaningful use requirements. We are also receiving many more substantive questions about the standards NLM supports. For example, Siemens, a major EHR developer, contacted NLM because they wanted to know how to implement RxNorm as the base standard in their medication module, and to employ NLM’s RxTerms, in order to help clinician data entry. We have more requests for making the standards available in different ways and for additions to the vocabularies. There is interest in more rapid additions to SNOMED CT, particularly to support development of value sets or specific lists of terminology needed for particular purposes such as quality measures.

NLM has not been able to add significant resources to deal with the increased demand, but the Library has two added more positions devoted to vocabulary standards and created a “Meaningful Use” Steering Group, composed of staff members from a number of different NLM divisions. Recent NLM activities designed to assist in the achievement of meaningful use criteria include a LOINC subset of frequently ordered tests and the inclusion of the VA’s drug classes in the NLM’s RxNorm distribution. The Library is working closely with ONC to get clarification on current priorities and resources for supporting key standards and on NLM’s role in the evolving national standards agenda.

## September 14-15, 2010 - Board of Regents

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Mr. James noted that the hard work NLM has done through the years has started to bear fruit in many ways, and proves how much in the “real world” NLM is. Dr. Joyce Mitchell agreed, remarking that, with meaningful use and EHRs, the Library is nicely positioned in the middle of high-priority national policy matters. This is a great opportunity to show that NLM is about more than indexing literature, but the Library staff must be stretched to the limit. Can the Board push for relief? A direct budget allocation from HHS would seem in order, to support the sections of meaningful use that Library is responsible for.

That would be very welcome, Ms. Humphreys replied. Unfortunately, NLM’s ARRA funds couldn’t be used for standards activities because there were strict limits on the types of NIH intramural programs eligible for the special stimulus funding. The ONC had money that could have been used but they also have many other priorities to support. ONC is looking at all the different standards that are required to achieve meaningful use and what should be the federal role in moving them forward.

Dr. Mitchell suggested that NLM explore one of the five “immediate next steps” Ms. Humphreys presented, to help vendors and users incorporate these standards. NLM could be more proactive by sponsoring workshops and conferences. These could be directly focused on the vendor community but also IT groups within doctors’ offices and hospitals. The ONC could support this, take it around the country and invite folks from IT shops who are struggling with the new elements. Ms. Humphreys said that she agreed with the importance of these kinds of programs. NLM has the world’s experts in some of these areas, but they are extremely busy so it is difficult for us to provide the type of advice and assistance that would be most helpful. We have to do better than we have done to date. Because resources are limited, consultant Dr. Holly Buchanan suggested that Webinars might be a good option.

Consultant Dr. Tenley Albright asked about the “menu” criteria. Basically, Ms. Humphreys said providers can exclude up to five criteria and still achieve “meaningful use”. However, the exchange of patient data in standard formats is *not* one of the requirements that can be deferred. Dr. Albright said that this has long been a stumbling block. Dr. Lindberg asked whether there was a there a comparable score card, to measure progress toward exchange of data between the VA and DOD. Ms. Humphreys replied that the EHR provisions in ARRA are directed toward Medicare and Medicaid providers so the VA and DOD are not directly affected.

Dr. Lindberg expressed concern that a state, like Maine, may decide to opt out of the national health reform provisions. What would that do to this EHR policy? Ms. Humphreys clarified that it is not a state’s decision, whether or not to adopt meaningful use; rather, it’s an individual hospital or physician practice that treats Medicare and Medicaid patients which must decide whether this is worthwhile or not. They can elect not to do it but, if they decide they can and will do it, they will receive incentives. Eventually if they can’t meet meaningful use criteria their Medicare and Medicaid payments will be reduced.

Dr. Carol Friedman observed that they may not be sharing information directly with their competitors but there are regional centers that are collecting large amounts of information and sharing it. Dr. Clem McDonald concurred, citing large pharmacy systems and the Indiana health information exchange. The movement is definitely there, Dr. Friedman said, like in the case of the New York Department of Health, which is helping physician practices to implement EHRs. She added that, with regard to a Webinar, if NLM offered something on meaningful use, not just standards but tools would probably be most helpful.

## September 14-15, 2010 - Board of Regents

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Dr. John Connolly commented that, as a provider, he often hears about incentives that would mean extra pay for Medicare. Is that the case here? Yes, Ms. Humphreys said, if you can demonstrate meaningful use, there would be some fairly substantial annual payments for a limited period of time.

Dr. Mitchell asked again whether the Board should do something to help NLM and the ONC get over this impasse; where there is not money coming to do these things and there is pressure to do more. Dr. Lindberg suggested that the Board wake up the US Office of Management and Budget (OMB) about the importance of this work. Mr. James commented that in times of very tight budgets NLM would have to allocate its resources to support such high priority initiatives,

### **XII. NLM AND SOCIAL MEDIA**

Melanie Modlin described how NLM has enthusiastically, but methodically, embraced social media. Once viewed with distrust by US government agencies, these tools, such as Facebook and Twitter, are now deemed powerful instruments of information sharing, not just by the general public but by the press and segments of the research community, too. HHS now has a Center for New Media, which keeps interested staff informed about policy and best practices. The NLM Office of Communications and Public Liaison (OCPL) reviews all requests to launch new social media outlets here, evaluating audience, message, staffing requirements, etc. That office also alerts HHS each time a new outlet is added.

The second most popular Web site after Google, Facebook has 550 million users. Twitter is the fifth most popular Web site, with 75 million users. Facebook provides a weekly snapshot of users and usage, and Twitter usage can be measured using free interfaces such as HootSuite and TweetDeck. NLM currently hosts four Facebook pages and 10 Twitter feeds, the most of any NIH Institute or Center.

NLM's Twitter feed for the press, nlm\_newsroom, did live tweeting at the E-patient conference held at NIH in April. Since then, that feed has picked up many prestigious followers, from the World Health Organization to E-patient Dave deBronkhard, with his 4,000 followers. NLM also follows over 100 opinion shapers, such as medical journalists and bloggers. Launched in August 2009, medlineplus4you is NLM's oldest and most popular Twitter feed.

What are the costs associated with social media? These outlets cost nothing to set up but do require care and feeding; content must be generated and comments and questions constantly monitored. Ms. Modlin invited to the Board to take copies of a draft version of NLM social media guidelines, prepared by NLM Associate Fellow Yani Yancey. NLM has the most social media vehicles of any NIH Institute or Center and has created a Social Media Engagement Committee, for sharing ideas and talking about challenges. What's next? An NLM You Tube channel is likely, to share video content connected with the 175<sup>th</sup> anniversary in 2011.

Mr. Hale discussed the use of social media by patients, health professionals and other federal agencies. He, too, mentioned e-Patient Dave deBronkard, a cancer survivor turned medical information and data sharing crusader. E-patients.net, to which he is a contributor, lets patients share information about their conditions, knowing that it may go to pharmaceutical companies, research institutions and marketing firms, to add to the body of research.

## September 14-15, 2010 - Board of Regents

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Next, Mr. Hale explained Twitter hashtags. By typing a hashtag or pound sign in front of a term, one allows all interested in that topic to find it with ease and follow related tweets. One example is #HCSM, the hashtag for Health Care Social Media.

Phil Baumann, an active health care blogger, last year wrote a post, “140 Health Care Uses for Twitter,” a nod to Twitter’s 140-character limit. Dr. Enoch Choi is a key player in MedHelp.org, a large patient and provider community where patients can receive consults from health professionals. Sermo.com is a community for accredited physicians, who can discuss health care issues in a space of privacy and professional courtesy. Dr. Kevin Pho is one of the better known medical bloggers (KevinMD.com), as is Dr. Val Jones, who has spoken at NLM and is a fan of NLM’s social media efforts.

Govloop.com was created to help federal employees and contractors better understand how social networking can be used to further the mission and vision of government organizations. A frequent contributor is Andrew Wilson, former head of the HHS New Media team. Many federal agencies are using social media very effectively. The Food and Drug Administration (FDA) is exemplary, having been spurred to action by the massive peanut butter recall. Their Twitter feed dedicated to food recalls now has 81,000 followers. The Centers for Disease Control and Prevention (CDC) stepped up social media engagement during the H1N1 flu outbreak; the White House gave them permission to extend their reach and that has benefited all federal agencies. The Environmental Protection Agency (EPA) has led the way in Facebook use, probably because so many citizens are engaged and interested in conversation about environmental topics. What happens when someone posts something inflammatory on your Facebook page? As many agencies have learned, you do nothing, because your supporters will defend you and also call for civility.

Next, Mr. Hale discussed Pillbox, NLM and FDA’s partnership to open up data related to pharmaceuticals to the general public. The site has been created using social networks as well. He showed the main Pillbox site and its Section 508-compliant drug identification system. Throughout the development process, NLM engaged clinicians, emergency medical technicians, patient groups and others, to improve the product. Still in Beta testing, Pillbox has saved at least one life by allowing quick identification of a medication.

Finally, Mr. Hale spoke about social media guidance and policymaking. The US Office of Management and Budget (OMB) provide substantial guidance on social media, albeit at a very high level. Leading by example, the White House is very social media-savvy, using blogs and YouTube to communicate information about pressing policy matters. Closer to home, the NIH Web Authors Group collects information on social media policy and guidance. Finally govsocialmedia is an open wiki formed by the federal Social Media Subcouncil, allowing the federal social media community to share practices in an informal setting.

Mr. James asked what the future of social media. Mr. Hale held up his phone and said that everything would be there, so that people do not have to log onto a computer or go to a Web site to obtain the information they needed. Ms. Humphreys pointed out that NLM is sharing application programming interfaces (APIs) with outside software developers, so usage increases by that method, too. Mr. Hale forecast a dramatic rise in the next five years in applications that make use of NLM APIs to get to NLM data, rather than people going to the NLM Web site for information. Ms. Humphreys added that roughly 40% of the use of PubMed, which we know is vast, is now thought to be via API interfaces. A portal page to all of NLM APIS is under development. Mr. James asked how NLM is faring compared to other

## September 14-15, 2010 - Board of Regents

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federal agencies, regarding social media. The CDC and FDA may be in the lead as far as social networks, Mr. Hale replied, but NLM is in front as far as electronic interfaces. He often hears from other federal agencies that they're eager for more NLM APIs. MedlinePlus, the Household Products Database and LactMed may be next, he said, and Ms. Humphreys added ClinicalTrials.gov to the list.

Dr. Buchanan asked whether NLM could create social media guidelines for libraries and other stakeholder institutions. She will review the draft social media guidelines. Mr. Hale mentioned a four-word mantra that Jeffrey Levy, a force behind much of EPA's social media successes, uses as a guide in development of any social media tool: Mission. Tools. Metrics. Teach. Those words offer a helpful structure to all organizations interested in venturing into social media.

Mr. James noted the incredible acceleration in the use of social media tools around the world and commended NLM for being at the leading edge, as it so often is, in matters of technology and communication.

### **XIII. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION**

Mr. James, the Subcommittee chair, said that the agenda for this body was short, because it centered on the Library's 175<sup>th</sup> anniversary, in 2011. He noted that most organizations, celebrating such milestones, shine the spotlight only on themselves, but that Betsy Humphreys had another approach in mind. He asked her to describe it to the Board.

This idea emerged when she conferred with Dr. Milton Corn, the anniversary chair. They hoped to enlist the Board to produce resolutions officially thanking key organizations with strong ties to the Library (e.g., the Medical Library Association, American Medical Informatics Association and the Society of Toxicology) for their support through the years. The Board might also like to thank Congress for legislative expanding the NLM mission, and for their support in funding us to do so. Mr. James remarked that this is the opposite of what one would expect—asking Congress to prepare a resolution supporting us. (We like that idea, too, Ms. Humphreys added.) Such thanks would carry the greatest weight in the form of a Board resolution, thanking these groups. If the Board approved this plan, NLM staff would prepare drafts for their consideration. AMIA is meeting in November 2010, so that one would go out early, with the others following. Ms. Humphreys hoped one or more Board members could be on hand to present each resolution, at an appropriate event.

Dr. Charles Rice of USUHS liked the idea and thought it would generate more and better coverage of the NLM anniversary by the organizations honored by resolutions, in their news outlets. They could mention the specific elements mentioned in the formal language. Mr. James said he hoped the Board could approve the first one, and perhaps give blanket approval to all, after that. Ms. Humphreys said that the group would probably be small—less than a dozen—and the Board may like to sign off on each. The AAMC is another one, Ms. Humphreys said, along with several federal agencies.

Mr. James said that he would soon recognize Dr. Corn, to talk more about the 175<sup>th</sup>, but that he wanted to Board to know about the carving of a special totem pole, which will travel cross country from Washington state before coming to the Library, where it will stand on the front lawn, in celebration of the Native Concepts of Health and Illness exhibition, opening at NLM next fall. Dr. Fred Wood of OHIPD discussed the 20-foot-tall totem, to be crafted by artist Jewell Praying Wolf James. The totem will make

## September 14-15, 2010 - Board of Regents

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about a dozen stops along the route, with ceremonies and events at each. Tribes, media, friends of NLM, politicians and others will be involved in these events. NLM has also commissioned a scale model of a hokole`a (voyaging canoe), which will be part of the exhibition. Board members expressed interest and asked for copies of the totem's travel itinerary.

### XIV. 175TH NLM ANNIVERSARY UPDATE

Anniversary committee chair Dr. Milton Corn gave an overview of activities planned. One leitmotif of the celebration is that, during the last 25 years, NLM has evolved from a trusted archive for ad hoc consultation by professionals into a core digital resource for scientists, clinicians and consumers, and an essential first stop for reaching a biomedically relevant goal.

The thematic thrusts of the celebration include taking pride in the past, clearly portraying the present and looking into the future. Audiences for the activities are the NLM staff, NIH in general, other federal agencies, users (professionals and the public), Congress and the Executive Branch, fellow libraries, the media, academia and international colleagues.

The planning effort for the anniversary has had a grassroots flavor, with over 60 NLM staff members involved in committees and anniversary activities suggested by any interested staff members, via an NLM anniversary Wiki. Dr. Corn showed a list of one-time events for staff, the media, our stakeholder groups, etc. There will be roughly one major activity per month and some phenomena that aren't date-specific, like a 175<sup>th</sup> anniversary Web site, a commemorative video and the artistic lighting of the NLM building, budget permitting. Mr. James suggested it would be appropriate to have the Friends of the NLM provide funding for the lighting. Having the building lit up would also be a great publicity tool. A new book, *Hidden Treasure: 175 Years of the National Library of Medicine*, will be illustrated with images from the History of Medicine collection. In April, we will hold a conference on storage of electronic health record data, along with the National Institute of Standards and Technology, National Archives and Veterans Administration. The Friends of the NLM are planning a June conference with a clinical trials theme and a formal dinner in September. In August, we plan to hold a session on "greatest hits" from among NLM's grant recipients. In November, a seminar for the media is planned, to reach traditional and new media.

NLM will plan special anniversary-themed activities in connection with annual meetings of the Medical Library Association meeting and American Medical Informatics Association, among other key groups.

We want to think clearly about NLM's future and how to convey messages about that. Dr. Corn also wants the Library to have a plan for follow-up to assess the impact of the events and activities of the anniversary year. Other guiding principles are to honor and showcase all NLM divisions and to employ social media effectively.

Ms. Tanji asked whether some of the NLM resources could be made into lesson plans. Alternatively, there could be a special 175<sup>th</sup> anniversary page for teachers and students, linking to the many resources appropriate for the various academic levels. Could we add that to the mix for 2011? Ms. Humphreys said that many such resources already exist, but we can definitely give them more publicity as part of the 175<sup>th</sup>.



## **September 14-15, 2010 - Board of Regents**

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### **XV. ADJOURNMENT**

The Board of Regents meeting was adjourned at 12:00 p.m. on September 15, 2010.

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

- Approval of the May 14-15, 2010 Board Minutes
- Approval of the October 4-5, 2011 Future Meeting Dates

Appendix A - Roster - Board of Regents

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

Donald A.B. Lindberg, M.D.  
Director, National Library of Medicine

Bruce James  
Chair, NLM Board of Regents