

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

**MINUTES OF THE BOARD OF REGENTS
September 11-12, 2012**

The 161st meeting of the Board of Regents was convened on September 11, 2012, 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 4:10 p.m., followed by a closed session for consideration of grant applications until 4:30 p.m. On September 12, the meeting was reopened to the public from 9:00 a.m. until adjournment at 11:45 a.m.

MEMBERS PRESENT [Appendix A]:

Dr. Joyce Mitchell [Chair], University of Utah
Dr. Ronald Evens, Washington University School of Medicine
Dr. David Fleming, University of Missouri School of Medicine
Dr. Katherine Gottlieb, Southcentral Foundation
Dr. Henry Lewis, Florida Memorial University
Dr. Trudy MacKay, North Carolina State University
Dr. Ralph Roskies, University of Pittsburgh
Ms. Mary Ryan, University of Arkansas for Medical Sciences Library
Ms. Gail Yokote, University of California, Davis

EX OFFICIO AND ALTERNATE MEMBERS PRESENT:

Dr. Regina Benjamin, Office of the Surgeon General, PHS
Mr. Christopher Cole, National Agricultural Library
Col. Dominic DeFrancis, United States Air Force
Dr. Joseph Francis, Veterans Health Administration
Ms. Kathryn Mendenhall, Library of Congress
Col. Cathy Nace, United States Army
Dr. Dale Smith, Uniformed Services University of the Health Sciences

CONSULTANTS TO THE BOR PRESENT:

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

SPEAKERS AND INVITED GUESTS PRESENT:

Dr. Krystl Haerian, Columbia University
Ms. Ruth Holst, National Network of Libraries of Medicine, Greater Midwest Region
Dr. Ronald Kikinis, Brigham and Women's Hospital, Harvard Medical School
Dr. Douglas Lowy, National Cancer Institute, NIH
Dr. Edward Sondik, Centers for Disease Control, DHHS
Dr. Robert Windom, Former Assistant Secretary for Health, DHHS

MEMBERS OF THE PUBLIC PRESENT:

Dr. Glen Campbell, Friends of the National Library of Medicine
Dr. Lynne Holden, Friends of the National Library of Medicine
Dr. Ronica Lu, Friends of the National Library of Medicine
Dr. Elliot Siegel, Consultant
Dr. Roy Simpson, Friends of the National Library of Medicine

FEDERAL EMPLOYEES PRESENT:

Ms. Betsy Humphreys, Deputy Director, NLM
Dr. Milton Corn, Deputy Director for Research and Education, NLM
Dr. Michael Ackerman, Lister Hill Center, NLM
Ms. Diana Almader-Douglas, Division of Library Operations, NLM
Dr. Sameer Antani, Lister Hill Center, NLM
Ms. Stacey Arnesen, Division of Specialized Information Services, NLM
Ms. Ione Auston, Lister Hill Center, NLM
Ms. Joyce Backus, Division of Library Operations, NLM
Ms. Kathleen Cravedi, Office of Communications and Public Liaison, NLM
Ms. Francesca Crawford, Division of Extramural Programs, NLM
Mr. Todd Danielson, Office of the Director, NLM
Dr. Dina Demner-Fushman, Lister Hill Center, NLM
Dr. Kathel Dunn, Division of Library Operations, NLM
Ms. Gale Dutcher, Division of Specialized Information Services, NLM
Dr. Valerie Florance, Division of Extramural Programs, NLM
Ms. Sheila Franco, Centers for Disease Control, DHHS
Dr. Dan Gerendasy, Office of Health Information Programs Development, NLM
Dr. E. Michael Gertz, National Center for Biotechnology Information, NLM
Ms. Karen Gutzman, Division of Library Operations, NLM
Ms. RoseMary Hedberg, Division of Library Operations, NLM
Ms. Sally Howe, Lister Hill Center, NLM
Dr. Michael Huerta, Office of Health Information Programs Development, NLM
Ms. Christine Ireland, Division of Extramural Programs, NLM
Ms. Janice Kelly, Division of Specialized Information Services, NLM
Mr. Kenneth Koyle, Division of Library Operations, NLM
Ms. Lisa Lang, Lister Hill Center, NLM
Dr. Robert Logan, Office of Communication & Public Liaison, NLM
Ms. Cindy Love, Division of Specialized Information Services, NLM
Ms. Jennifer Marill, Division of Library Operations, NLM
Ms. Christie Moffatt, Division of Library Operations, NLM
Dr. Clement McDonald, Lister Hill Center, NLM
Mr. Dwight Mowery, Division of Extramural Programs, NLM
Mr. David Nash, Office of the Director, NLM
Dr. Aaron Navarro, Lister Hill Center, NLM
Dr. Steven Phillips, Division of Specialized Information Services, NLM
Mr. Kevin Read, Division of Library Operations, NLM
Dr. Jeffrey Reznick, Division of Library Operations, NLM
Dr. Angela Ruffin, Division of Library Operations, NLM
Mr. Jerry Sheehan, Office of the Director, NLM
Dr. Hua-Chuan Sim, Division of Extramural Programs, NLM
Dr. Naga Shanmugam, Centers for Disease Control, DHHS
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 Programs Development, NLM
Dr. Jane Ye, Division of Extramural Programs, NLM
Dr. Terry Yoo, Lister Hill Center, NLM

I. OPENING REMARKS

Dr. Joyce Mitchell, NLM Board of Regents Chair, welcomed the Regents, alternates and guests to the 161st meeting of the Board. She noted that NLM Director Donald Lindberg would not be in attendance due to a recent fall. She reported that NLM Deputy Director Betsy Humphreys would be representing him during the Board meeting. She introduced new Board members Ms. Gail Yokote and Dr. Joseph Francis, and United States Surgeon General Dr. Regina Benjamin.

II. REPORT FROM THE OFFICE OF THE SURGEON GENERAL, PHS

Dr. Regina Benjamin noted that preventing suicide is a priority for her office. She observed that nearly 100 Americans die by suicide daily and that more than 8 million Americans thought about suicide last year. She reported that the Office of the Surgeon General (OSG) released a national suicide prevention strategy yesterday that details how communities and individuals can help prevent the burden of suicide and suicidal behavior. The OSG believes that suicide is preventable. Activity in this field has grown dramatically since 2001. The OSG established a suicide prevention resource center and a 1-800-TALK hotline, increased training and developed awareness programs. The OSG found that the connectedness to families, teachers, co-workers and institutions can help protect people from a wide range of health problems. They now have evidence of the effectiveness of intervention strategies. They recognize the value of coordination and prevention efforts and new methods of treatment and patient follow-up. The bottom line is that the OSG found that by working together we can prevent suicide. However, partnerships and the concern of health professionals will be required. The Surgeon General reported that a public service announcement (PSA) was released at a press conference to brief reporters about the seriousness of suicide and her Office's suicide prevention strategy. The PSA was shown.

Dr. Benjamin was asked if particular populations were more likely to commit or consider suicide. She reported that the OSG knows, for example, that middle-aged men have the highest suicide rate. The LGBT community also has a high rate of suicide. But no population group is immune. Sixteen percent of high school students said that they have thought about suicide. Dr. Joseph Francis of the Veterans Health Administration asked whether the OSG was gathering good public health data. She reported that the OSG was gathering data that was guiding the prevention strategy and working with the VA as well.

III. ADVANCES AND CHALLENGES IN CONTROLLING HPV-ASSOCIATED CANCERS

Dr. Douglas Lowy, Chief of the Laboratory of Cellular Oncology in the Center for Cancer Research at the National Cancer Institute (NCI), and Deputy Director of the NCI, reported on the Human Papilloma Virus (HPV) vaccine. He is the inventor of the NIH vaccine technology that has been licensed by Merck and GlaxoSmithKline, the two companies that manufacture the vaccine. He noted that there are four major oncogenic agents in the world that cause cervical cancer. The discovery of HPV as a main cause of cervical cancer by German virologist Harald

zur Hausen and colleagues led to a Nobel Prize in 2008 and an explosion of information about this disease, including the natural history of the HPV infection, the pathogenesis of this disease, and the identification of other HPV-associated cancers. Dr. Lowy noted that virtually all cervical cancers are attributable to an HPV infection and displayed a chart comparing cervical cancer and HPV between developing nations and the United States. He estimated that the incidence of cervical cancer has gone up three-fold in the last 25 years. About a third of cases of HPV-associated cancer in the United States affect males, and two-thirds affect females. He noted that more than a dozen HPV types are causative of cervical cancer. But HPV types 16 and 18 cause about 70%. Both of the FDA-approved vaccines are directed against HPV 16 and 18. There are about 20 million HPV infections per year, or about one in five sexually active women per year will get a new HPV infection. Most of those infections are self-limited and undergo spontaneous clearance and regression. If it is HPV 16 and 18, they progressively account for a substantial proportion of the high-grade dysplasia and invasive cancer. The vaccine is very safe and is close to preventing 100% of the HPV types targeted. An issue about the duration of protection was paramount when the vaccine first came out. There is reason to believe, based on statistics and research, that the duration of protection will be substantial. We spend about \$8 billion per year on HPV-associated disease but more than 80% of that is spent on cervical cancer screening. The NCI is working with the FDA and the companies that make HPV vaccines to see if this might be a way of increasing the availability and access to cervical cancer screening. The NCI Center for Global Health is working with the CDC to develop more affordable screenings and vaccinations. Dr. Lowy was asked what was the best age for vaccination —13 or 16? He responded that it is really important to vaccinate before people become sexually active because the vaccine does not prevent existing infection. The CDC, he noted, recommends vaccination at ages 11 and 12. He reported that there are a substantial number of ninth graders who are sexually active and some with four or more partners. Dr. Lowy was also asked if screening resulted in savings for cancers caught. He said that he was not trying to suggest that money would be saved by preventing cancer and noted that it would be impossible to compare countries because we have three to four times the screening than others do. He was also asked to explain why he did not recommend giving the vaccine to any adult woman. He replied that the FDA has not approved the vaccine for people over the age of 26. The issue is that although you can prevent the infections, the majority of women over age 26 have already had one of the infections by that time.

Dr. Benjamin said we should vaccinate young girls sooner, before they become sexually active. Dr. Lowy remarked that the CDC has some negative data surrounding vaccination at an earlier age, but that in the future we may move the vaccination age down to even younger people, so that there is a separation between sexual connotation and vaccination.

Dr. Mitchell observed that men and women change partners, get divorced. Shouldn't they get vaccinated? Dr. Lowy agreed that it would not be unreasonable for them to be vaccinated.

IV. FORWARD FOCUS WORKSHOP: PART OF THE NIH COMMON FUND STRATEGIC PLANNING PROCESS

Board member Dr. Ronald Evens reported that the Web site for the NIH Common Fund Program Life Cycle states that, "The Common Fund is intended to be a flexible resource for NIH to make strategic investments in programs that will have high impact NIH-wide. Strategic planning is

undertaken regularly to identifying research areas that address key roadblocks in biomedical research or that represent emerging scientific opportunities ripe for Common Fund investment.”

The Common Fund was created by Congress through the 2006 NIH Reform Act to support cross-cutting, trans-NIH programs that require participation by at least two NIH Institutes or Centers or would otherwise benefit from strategic planning and coordination. Dr. Evens reported that the strategic planning process for identifying programs to be supported by the FY 2013 Common Fund has used several mechanisms to generate a set of preliminary program concepts from which the programs to be funded will eventually be selected. These include use of social media, a request for ideas from NIH Institutes and Centers, and meetings of outside experts to generate and discuss potential ideas. The meetings included three “Forward Focus Workshops” held in May 2012 in Chicago, San Francisco and Potomac, MD. At Dr. Lindberg’s recommendation, Dr. Evens was invited by NIH to participate in the Maryland event. He reported that there were about 30 participants who were divided into three groups, including social scientists. Of the many innovative proposals generated, participants voted on five to be presented to NIH Director Dr. Francis Collins. The funding proposals we supported were heavily extramural-oriented and the money has to be spent within five years. Dr. Evens reported that the final decisions will be reported at a later date.

V. MAY 2012 MINUTES AND FUTURE MEETINGS

The Regents approved without change the minutes from the May 2012 meeting. It was agreed that the winter meeting will be February 5-6, 2013, the spring meeting will be May 21-22, 2013, and the fall meeting will be September 17-18, 2013.

VI. REPORT FROM THE NLM DIRECTOR

Board chair Dr. Mitchell introduced Dr. Cathy Nace, Director of Medical Education in the Office of the Army Surgeon General, and NLM Deputy Director Betsy Humphreys.

After expressing regrets that Dr. Lindberg was unable to deliver his report, Ms. Humphreys noted that NLM has been very effective in spending its FY 2012 appropriations. As for the FY 2013 budget, \$380.9 million was included in the President’s budget request for the NLM. She expects that the House and Senate will pass a six-month continuing resolution (CR) with White House support. This stopgap spending measure should provide funding at a comparable FY 2012 level for the first half of FY 2013. The potential effect of sequestration in January 2013 on the six-month CR is uncertain. More may be known when the OMB releases funding guidance. Assuming the CR passes, it will then take a while to find out what that means. Clearly, she observed, a flat budget is a good scenario in the current environment

Ms. Humphreys reported that Sheldon Kotzin retired after 44 years at the NLM. Nadgy Roey also retired. She came to NLM as a personnel specialist, then personnel officer, and finally became the NLM Deputy Ethics Coordinator. She was a fantastic person, a delight to work with and will be missed. Loren Frant is the new deputy chief of the Public Services Division. Kenneth Koyle is NLM’s new deputy chief of the History of Medicine Division. Dr. Dan Gerendasy joined NLM as the new chief of International Programs. Dr. Clem McDonald introduced Dr. Raymond Francis Sarmiento and Dr. Szilard Vajda, both new Lister Hill Center Fellows. Kathel

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Dunn introduced NLM's new Associate Fellows are Diana Almader-Douglas, Karen Gutzman, RoseMary Hedberg and Kevin Read.

Ms. Humphreys called upon NLM Assistant Director for Policy Development Jerry Sheehan to provide an update on legislation. Mr. Sheehan reported that the Trial and Experimental Studies Transparency Act, The TEST Act, was introduced about a month ago. It would expand the requirements for clinical trial registration and results submission in ClinicalTrials.gov. Ms. Humphreys noted that there is a summary in the Board book on Public Access Policy, but nothing particularly new to report. She also called upon the Board to review the summaries after Tab E on the NLM Memorandum of Understanding with the National Endowment for the Humanities, and Tab H on a Special Display in Cooperation with the National Museum of American History. Both, she noted, are efforts by NLM's History of Medicine Division to follow up on recommendations from the Board in past years to do more things with other federal agencies to educate other audiences about the work and services of the NLM.

This is the tenth anniversary of MedlinePlus en español. Information about its success as a source of consumer health information is detailed in Tab G. MedlinePlus en español is frequently among the top five on the American Customer E-Government Satisfaction Index.

Ms. Humphreys encouraged the Board to read about the informatics training conference under Tab I. It showcased many of NLM's 260 trainees.

She concluded the Director's report by presenting a short video clip from a June 9, 2012 *Washington Journal* segment of C-SPAN TV featuring Dr. Lindberg's responses to questions from health care professionals and the public regarding electronic health records.

VII. CDC'S *HEALTH US IN BRIEF*: THE INTERACTIVE VERSION VIEWED THROUGH NLM'S PANORAMA

Dr. George Thoma, Chief of the Lister Hill Center Computer Science Branch, reviewed the evolution of an in-house research effort to investigate methods to create Interactive Publications and to develop tools for authoring, visualization and analysis, including the Panorama visualization/analysis tool. Originally downloadable Java software, the latest version of Panorama relies solely on a Web browser. In collaboration with the National Center for Health Statistics (NCHS), an arm of the CDC, NLM is using this version to view and analyze the NCHS's widely distributed annual publication, the *Health, United States: In Brief*. This document presents national trends in health statistics, and features information on morbidity, mortality, health care utilization, risk factors, and prevention, insurance and personal health care expenditures. Panorama makes the many charts, graphs and tables in the document dynamic, and allows users to conduct in-depth analysis of the data in an interactive way.

NCHS Director Dr. Edward Sondik noted that his agency is one of the federal statistical agencies but, unlike others in that category, they produce all of their data independently. They have a very broad mandate of monitoring the health status of the population and also how well the health care system operates. It is both a blessing and a curse that NCHS has a wealth of data on what's happening in clinics, hospitals and nursing homes, as well as insurance rates, incidence of chronic conditions, etc. The challenge has been to drill down from national data to local data,

and also how to get this data out at the highest quality to those who can put it to good use. The collaboration with NLM is very exciting. It will help convert the current two-dimensional data of *In Brief* into a more versatile, dynamic and useful tool. NCHS health statistician Sheila Franco then gave a demonstration of the interactive *In Brief* document.

VIII. PRESENTATION OF REGENTS' AWARD

Dr. Mitchell presented the Board of Regents' Award to Dr. Michael Gertz. Dr. Gertz is a staff scientist within the Computational Biology Branch of the National Center for Biotechnology Information. He received this award for identifying two previously unrecognized immune deficiencies. He was a significant contributor to projects that identified STK4 deficiency and LRBA deficiency, allowing these conditions to be better diagnosed.

IX. DISASTER INFORMATION SPECIALIZATION PROGRAM

NLM's Disaster Information Management Research Center (DIMRC) contracted with the Medical Library Association (MLA) to create a continuing education program for librarians and other professionals who want to develop a specialization in disaster information to assist with institutional and community disaster preparedness and response efforts. Cindy Love, with DIMRC, and Ruth Holst, Associate Director of the NNLM's Greater Midwest Region and a past president of the MLA, provided details.

As Ms. Holst was starting her term as MLA president in 2010, Ms. Love asked whether MLA would be interested in developing a disaster information specialization CE program. It dovetailed with Holst's efforts to encourage MLA members to rethink the role of librarians and develop new areas of expertise. It also fit with NLM's Long Range Plan 2006-2016, to "ensure continuous access to health information and effective use of libraries and librarians when disasters occur."

MLA began work in September 2010, surveyed librarians' interests, and developed an initial course on disaster information resources. In the second year, five new courses were developed and taught. The specialization program has a basic level with 15 credit hours and an advanced level with an additional 12 credits. Content ranges from the basics of disaster information resources to exploring the ethical and legal aspects of response. The accreditation lasts for three years and can be renewed by taking additional courses.

Holst noted the specialization has several benefits to people inside and outside MLA. Classes are taught in-person and online to ensure greatest possible access. Participants receive a certificate formally acknowledging their effort. In addition to health sciences librarians, the specialization is open to: librarians in public, academic and corporate libraries; allied health professionals; public health workers; and anyone interested in ensuring access to health information in disaster situations.

Ms. Love noted there has been a lot of interest in the training, as well as positive feedback. To date, there have been 15 classes with 420 participants from 44 states, four provinces and five countries. A survey of the first group of participants found that 52% planned to complete the

basic certificate, 29% planned to complete the advanced certificate. More than 90% of those surveyed said the training contributed to their awareness of the roles librarians can play in disasters and their awareness of information needs during a disaster. They add more courses; increase the number of instructors; and improve the online courses.

Following the presentation, Dr. Evens suggested plugging into the curriculums of other programs and offering courses demonstrating what the librarian can do for first responders. Board consultant Dr. Marion Ball suggested integrating the courses into nursing curriculums. Board member Dr. Henry Lewis said he hoped NLM's Environmental Health Information Outreach Program would have the opportunity for this training as well.

Board member Mary Ryan asked whether people returning from disasters have been queried about their needs. Ms. Love said the Uniformed Services University of the Health Sciences (USUHS) library and the NIH Library have interviewed military people who had been deployed to disasters, to ascertain the types of humanitarian assistance they thought would be beneficial.

Board member Dr. David Fleming asked whether NLM is doing anything to make sure first responders have access NLM's information. Ms. Love said NLM is developing mobile apps and mobile-enhanced web pages to help people get to that information. Ms. Gale Dutcher, Deputy Director, SIS, said that her office has developed important tools such as WISER, CHEMM, and REMM, which deal with hazardous chemicals and radiation for mass casualty events, and they are working with first responders and first receivers to make sure they have access to those products and don't have to worry about Internet connectivity. NLM Deputy Director Betsy Humphreys added that disaster information is the area where NLM should be most concerned with a downloadable app that's easily accessible on users' handheld devices. Board member Ms. Gail Yokote asked whether there's a way to get this information to public libraries. Ms. Love said NLM has had people in training classes from school libraries, public and academic libraries.

X. OPEN*i* AND BIOMEDICAL IMAGE SEARCHING

Drs. Sameer Antani and Dina Demner-Fushman of the Lister Hill National Center for Biomedical Communications (LHNCBC) presented their research and development project called *Open*i** (pronounced "open eye"). It enables users to access visual information from biomedical articles that are relevant to their query, as well as the article's take-away messages.

Dr. Demner-Fushman explained the rationale for the project. Several studies confirm the importance of images in communicating information and recognize the need to develop tools to access both images and the articles. That need meshed with existing LHNCBC research and development initiatives in text processing, image processing and information retrieval. A feasibility study was done on a small subset of full-text articles from radiology journals. Dr. Matthew Simpson built a search engine that was then developed into the *Open*i** system.

The goals of *Open*i** are to: provide direct access to relevant images from image databases and literature; improve the relevance of the biomedical literature search results by targeting the visual content in the articles; and find information relevant to a patient's medical case, when given access to the patient's electronic health record.

The system is based only on the publicly available, open access PubMed Central, thereby avoiding copyright issues. To create a document collection available to the public, the team uses: documents from PubMed Central; the original citations from PubMed; and MedlinePlus health topics to link out to that resource. The full text of the article and the images in the article are then processed—bibliographic and meta-information as well as captions and the discussion of the figures in the full-text of the paper are extracted. They are then mapped to the UMLS to create a structured representation of the article. Images are then classified by type, x-ray or graph, for example, and then translated into words. The end result is an enriched citation that has both traditional information and image information encoded in words which can be indexed by a standard search engine.

Openi has features that distinguish it from purely text-based search engines. *Openi* provides: the ability to search by an image; links to PubMed Central articles, MedlinePlus articles and PubMed citations; multiple views of the images and papers; and the ability to do advanced searches by image modalities, journal type and clinical specialties. Other features include automatic query expansion; ranking according to specific clinical specialties and free search and complex queries.

Dr. Antani detailed the system behind *Openi* as well as its usage. *Openi* averages about 4,500 unique visitors per day. The current data set is 1.2 million images served from 450,000 articles. *Openi* has climbed up Google's rankings. If you search for images in Google Images, results are often from *Openi*. Plans are to expand the collection and enhance query and search capability.

Dr. Fleming called the work exciting and asked what's being done to evaluate how the information is being accessed, who's accessing it, what the outcomes are and what the industry is doing. Dr. Demner-Fushman said she and Dr. Antani are involved in organizing the evaluations. In general, the information retrieval community is struggling with understanding effectiveness when doing batch evaluations, so they would welcome any ideas. Dr. Antani added that in terms of the industry question, this is public access and we have at least thought about opening up some of the services that go into the processing, but it has to be balanced against the interests of allowing public queries to come in on their images, and indexing their material.

Board member Dr. Ralph Roskies asked how many features you look at in each image. Dr. Antani explained they go through a feature selection process. They extract all features and then eliminate those which are not relevant for a particular class of images. Ex-officio alternate Board member Dr. Cathy Nace asked what's being done with dermatologic lesions, who the current users are, and whether the system has been piloted. Dr. Demner-Fushman said five clinicians did preliminary evaluations, but more evaluations are welcomed.

XI. PHARMACOVIGILANCE AND REPURPOSING MODEL AND APPLICATION: A CASE STUDY

Krystl Haerian, MD, with the Department of Biomedical Informatics at Columbia University, told the Board about the pharmacovigilance and repurposing studies in which she is involved. Dr. Haerian won a "people's choice" award at NLM's Informatics Training Conference.

The researchers use electronic health record data in their work, which is two-fold. The team is trying to detect, assess, understand and prevent adverse side effects or any other drug-related problems. The team also explores drug repurposing. The goal is to find an informatics solution to address three needs: the expensive and lengthy drug discovery process that creates a need for drug repurposing; the incomplete safety profile that creates a need for pharmacovigilance; and the need for basic science lab findings testing in humans.

Dr. Haerian highlighted a case study of valvular heart disease, which was chosen because it's a serious disease affecting 2 million people in the US. She then described the model the team developed. The researchers start with unstructured EHR data (free-text notes that the physicians write) and process it with a natural language processing system called MedLEE. Dr. Carol Friedman, a former NLM Board member and Dr. Haerian's advisor, developed the system. MedLEE extracts structures and encodes the clinical information in the narrative patient reports applicable to a broad range of clinical domains and diverse applications. After MedLEE is used, the researchers identify the event and apply appropriate exclusion criteria to identify the patient cohort. The team uses regression analysis to establish a hospital level prevalence of an adverse event and patients on a specific drug. If the adverse event rate is greater than the baseline, it might be a good place to look for post-market pharmacovigilance signals. If it is less than baseline, it might indicate a good place to look for drug repurposing signals. The valvular heart disease study involved 85,539 patients at New York Presbyterian Hospital. Mitral valve insufficiency was used as a surrogate marker for valvular heart disease because medications have been removed from the market for affecting the mitral valve and causing valvular insufficiency. The top 25 dispensed drugs in 2010 were explored. The team found a pharmacovigilance signal for known valvopathogens, and also a signal of interest for drug repurposing.

Ex-officio Board member Col. Dominic DeFrancis, representing the Air Force, asked whether they've ever found a drug that give signals for both pharmacovigilance and repurposing. Dr. Haerian said not so far, but it's possible they could find that as they study other conditions. Dr. Mitchell asked whether the team plans to bring the findings to the drug repurposing community. Dr. Haerian said she presented at the Drug Information Association meeting and spoke with people from two drug companies. Ms. Humphreys noted that Dr. Friedman, an original developer of the MedLEE system, was part of the Columbia group that was an original UMLS contractor. Because of Dr. Friedman and others, plus NLM's own natural language processing group, there was a strong push to use UMLS in natural language processing.

XII. EXTRAMURAL PROGRAMS REPORT

Dr. Valerie Florance, NLM Associate Director, Extramural Programs (EP), updated the Board on NIH's proposed special counsel review. This requires a look at applications from investigators with \$1 million or more in direct costs of research support before any NIH institute makes another award to them. The review applies to competing research grants, such as R01's and R21's. Training grants, some big center grants, diversity and reentry supplements are excluded.

Funded or committed research grant awards in the same fiscal year as the application are under consideration for special council review. Given that investigators may receive grants from multiple Institutes, EP staff will run a report to determine if EP has any applications from investigators who meet the threshold. If so, EP will write up a recommendation based on the

uniqueness of the project and present it to the Board's EP subcommittee. If the subcommittee accepts the recommendation, it will be presented to the full Board for a vote. Dr. Florance asked the Board to approve a change in EP's operating policy. It was approved unanimously.

Dr. Florance provided an overview of EP activities for FY2012. EP will make 137 awards totaling \$44.2 million. New grants account for \$17.2 million. Continuing grants account for \$26.9 million. Dr. Florance gave a sampling of titles and topics of the awards. For example, there's an award for a mass casualty management system. Bioinformatics as well as translational continue to be robust parts of NLM's funded research portfolio. In the scholarly works program, EP gave five new grants of \$50,000 to allow someone to buy their time back to write a book. EP also awarded 14 new five-year training awards. EP rearranged its priorities to bring more MDs and PhDs into the programs, and restricted the number of pre-doctoral trainees. NIH's National Institute of Dental and Craniofacial Research now is funding dental informatics at three of NLM's training programs. EP also has more people involved in its short-term training position (STTP) program. These are three-month training positions focused on underrepresented ethnic and minority groups, women, the disadvantaged, and the disabled. This year, EP awarded eight administrative supplements to research grantees of other NIH Institutes to bring librarian informationists into their research projects. Dr. Florance hopes to offer this program every year. Ms. Humphreys said Dr. Lindberg was very pleased with the response and the interest from other NIH Institutes and Centers.

Dr. Florance then provided a view of NLM's active grant portfolio for FY2012 which includes 230 projects, worth about \$83.7 million. About half of our money goes into research, about 25% goes into training, the rest into resource and career awards. 200 articles were published by NLM grantees in 2012.

XIII. RE-IMPLEMENTATION OF THE INSIGHT TOOLKIT

Dr. Michael Ackerman from the Office of High Performance Computing and gave a quick review of the Visible Human Project (VHP), one of NLM's most highly regarded and well used R&D projects, developed in the mid-1990s. Although the VHP presented a wealth of varied data— MRIs, CT scans and cryosections—it was all two-dimensional. Although thrilled by the project, users soon began telling NLM that what they really needed was the three-dimensional (3D) object. Staff decided that the wisest course would be to provide them with the tools to take the cross sections and create the 3D objects themselves. That was the genesis of the Insight ToolKit (ITK), a publicly available software package for high-dimensional (3D, 4D and higher) data processing supported by NLM and its partner Institutes and other federal agencies. ITK has been providing a software foundation for biomedical image research and development for over a decade.

Dr. Terry Yoo then gave a brief history of the ITK, its usage and growth. Even in times of lean funding, the ToolKit has seen widespread use by researchers in many countries. In the last 12 months alone, there have been almost 60,000 downloads of the ITK, and it has over 2,500 registered users. In 2009, NLM decided to initiate a contract project to update the ITK open-source image processing software library to take advantage of newer, faster graphics processing units, to simplify the interface by providing scripting tools and language bindings, and to enhance and expand ITK by adding interfaces for file formats in radiology and microscopy.

In June 2010, NLM made awards to 16 different universities, companies, clinics and centers using funds from the 2009 American Reinvestment and Recovery Act (ARRA). The project moved at a very rapid pace, once funded. They assembled the team, a constellation of people from large and small companies, engineering schools, medical schools, etc. GE Global Research joined in this effort, having incorporated the previous version of ITK inside their commercial products.

Dr. Yoo then described other applications of the ITK, for example, at the University of Utah's Scientific Computing and Imaging Institute and the Harvard University School of Engineering and Applied Sciences. He described the challenge of converting existing algorithms into parallel computing on the graphics processing units (GPUs) and other technical problems to work out. NLM has wanted to lower the barriers for entry to the ITK in terms of the programming. Just last week, a new, simple ITK was released and met with praise.

In summary, Dr. Yoo said NLM spent the money wisely, employed people as ARRA intended, built infrastructure, and shared the product, the updated software, freely with the public. He then introduced Dr. Ron Kikinis, the head of the Surgical Planning Laboratory at Harvard Medical School, Brigham and Women's Hospital, and director/principal investigator of the National Alliance for Medical Image Computing (NAMIC), one of the NIH-funded National Centers for Biomedical Computing.

Dr. Kikinis said that he is principal investigator (PI) for the Slicer project, which has been his primary focus for the past decade. Slicer uses ITK at its core for subject-specific analysis. Their approach is compatible with ITK's, using free, open source software and making it available on different operating systems. Built into the architecture is the capability to extend the software with your own functionality. Backing this up is the NAMIC, which is creating and maintaining this platform which includes ITK. Dr. Kikinis is also the PI for P41 National Resource Center, where his team is more focused neuroimaging analysis research and is also using Slicer. Those two efforts leverage each other. The hurdle is to get from a prototype that lives in the computer of a graduate student to a tool that the biomedical researcher can use after the student graduates. The question is, can it be done, and is it worth doing? Creating reusable tools requires engineering, industrial strength engineering—it's often more costly than the original algorithm research. This type of work is not really innovative so it doesn't fit into the NIH funding criteria. But in the field of medical image computing, you cannot get effective patent protection so the companies are not willing to take the risk to invest until you have demonstrated that it's worth doing. Dr. Kikinis described this nether region as "The Valley of Death," where all the algorithms go to die. He and his team are trying to build a bridge across this valley by providing the entire commodity infrastructure that is needed so that translation can be done with significantly less effort. In order to show ITK at work, Dr. Kikinis then used Slicer to show a virtual brain MRI (magnetic resonance imaging).

Dr. Roskies asked about the ITK files—are they all generated internally or can other people contribute them? They are contributed from outside, Dr. Yoo responded, but all of the algorithms submitted have to be working and compilable. Dr. Evens remarked that two major trends in education today are online education and simulation. Is ITK relevant in those areas? Yes, replied

Dr. Yoo, regarding online education. For example, one of their partners is the Carnegie Mellon University Robotics Institute. An instructor there is teaching revised ITK for medical image processing and making all of his lab manuals and programs freely available. Dr. Kikinis was showing interactive manipulation, and it looks very similar to the wind tunnel simulations that we saw 20-30 years ago. We're enabling the simulation, in a way. It's not a mandate that ITK participants do online education, but we are certainly producing raw material from which courses can be constructed.

Dr. Roskies asked about segmentation, and where we stand with that? Some segmentation tasks are easy, said Dr. Yoo, while others are challenging. When we're able to marry the things that humans are good at, like making judgments about visual content and figuring out what's what, with what computers are good at—measurement and quantitative analysis—that's where we make the greatest strides. In the Visible Human data, for example, where the tendon ends and the muscle begins is hard to pinpoint. Even anatomists will draw a fuzzy line somewhere in there and that's the space that delineates the two. These complex problems require that kind of subjective judgment to be interactive and insertable into the video analysis.

Dr. Ball asked how users are taking ITK from theory into practice. Are neurosurgeons actually using it in their practice? If so, how this is advancing the field? Dr. Kikinis told her that 3D slicing research is not intended for routine clinical practice. But at the hospital where he works, they have a large image-guided therapy department and are experimenting with Slicer. He does the research and shows them the findings, and elicits their ideas for putting those into practice.

Dr. Evens said the standard of care these days is 3D CT slices. The problem for today's radiologist is it's not just 10 slices but more like 100 3D slices that they're trying to keep up with, manage that in a reasonable time period, and also convey what's on the images to the surgeon or somebody else who needs them. The issue is how to manage all of the data. Dr. Kikinis agreed, saying that there is much left to do, and that segmentation will continue to be an important consideration, so that medical professionals can isolate the areas of greatest interest.

XIV. DIMRC WORKING GROUP REPORT

SIS Director Dr. Steven Phillips said that NLM has been providing information and support for preparation of response disasters for more than 25 years. In 2008, this effort was codified and DIMRC was established as part of SIS. Its mission is to support the information needs of the disaster, preparedness and response community. Since its creation, DIMRC has led trans-NLM efforts to organize salient literature and to create tools for first responders and first receivers (at hospitals and other facilities), and has conducted training using varied technologies. DIMRC has been involved in developing ham radio networks, to serve when normal communications channels fail, and has developed partnerships with other agencies, nationally and internationally.

The Board of Regents asked SIS to set up a working group to provide guidance on DIMRC's future activities. Dr. Phillips noted that many recognized experts serve on the group and gave a sampling of questions posed to the Working Group:

- What should NLM do to use its strengths and capabilities to support these activities?
- Are our current activities efficacious and useful?

- What level of staffing should we have?
- How much money should we spend on this?
- How can NLM strategically integrate its existing programs in supporting these efforts?

Dr. Phillips then introduced Dr. Robert Windom, former HHS Assistant Secretary for Health and the current chair of the DIMRC Working Group. Dr. Windom said that the Group recommends NLM seek more direct legislative authority for DIMRC. That authorization should bring with it acceptance by Congress, and clout from the peers and people you want to work with. This status would make NLM and DIMRC a partner with other disaster programs in the US, such as the Stafford Act, the Pandemic and All Hazards Preparation Act, and the Presidential Policy Directive. He shared language about DIMRC from a recent Senate Appropriations Committee Report, and said that that was the wording that should be used for the authorization.

Dr. Windom described the three essential elements of emergency preparedness: education, public input and transparency. He said that emergency responders, medical professionals and public health experts are important participants, but the medical librarian must be a part of the team internally, and in the community as well. He described a successful pilot center in Sarasota, which has been funding a disaster information specialist librarian for three years. Dr. Windom asked that the Board consider making the Group a long-term advisory body.

DIMRC Director Stacey Arnesen described DIMRC's partnership with the HHS Office of the Assistant Secretary for Preparedness and Response (ASPR), the lead agency in the federal government for medical and public health preparedness and response to disasters in public health emergencies, and how that office already looks to DIMRC for new technologies, as they did with regard to medical surge and patient movement following Hurricane Isaac. Ms. Arnesen said that the Working Group suggested NLM focus its disaster-related efforts on literature and terminology as opportunities to advance information management and disaster medicine and public health that play to NLM's strengths and capabilities. The Group commended the work that we had done to ensure that disaster publications were included in PubMed and that the MeSH vocabulary was expanded to address encompass additional disaster topics. Members noted, however, that it is important to include non-journal literature in our database for first responders and others on the front lines. With input from this group, NLM has revised its collection scope and coverage statement for this area and is working on revised selection criteria.

Ms. Arnesen showed a video about the Bethesda Hospitals' Emergency Preparedness Partnership (BHEPP), of which NLM is a member. It features several technologies developed by NLM, including the patient tracking system, which won an HHS *Innovates* award last spring. She said that DIMRC and its trans-NLM partners are creating many individual products but should probably adopt the NCBI model, working to become the recognized leader in this area of research. She next discussed evaluation. Evaluating health information is always a challenge. A recent hot topic has been the use of social media in disasters and in evaluating disaster information. It's been fascinating, she said, to read the comments about how NLM should devote time to curating disaster information, validating it and turning it into something useful. In light of this, it seems smart to bring librarians to the table regarding social media and how it can be used for situational awareness, as well as community resiliency.

Echoing Dr. Phillips, Ms. Humphreys pointed out that NLM has been doing this work for a long time and is not doing something it's not authorized to do. However, a more direct and specific authorization could raise NLM's visibility with other Federal agencies and organizations working in this area and get us a place in relevant conversations earlier.

In terms of the notion of continuing this Working Group, the Board can have ad hoc working groups but they have to have a set term. We'll have to look at this in the context of the federal advisory committee structure. She said she'd like to explore options and present those at a future Board meeting.

Dr. Evens wondered whether data management experts and librarians really needed to be on site at disasters, along with emergency responders and medical personnel. How high up on the list of NLM priorities does this need to be?

Dr. Phillips pointed out that the federal Stafford Act, governing disaster response, has been amended to include libraries as key resources. Ms. Humphreys remarked that Dr. Lindberg is very interested and committed to this area. He feels that management of and preparation for disasters is a major public health issue in the US. He has a strong opinion that it is largely an information problem that people experience in the midst of disasters. Dr. Lindberg feels that if you don't focus on this as an information problem and come at it from that aspect, looking at research informatics and related issues, you may never get a handle on how to do better when these things occur.

Col. DeFrancis asked whether NLM envisioned the role of the information professional in disasters as an organizer of information or as a real-time responder on the ground at the event. Dr. Phillips responded that, based on his experience following the Haiti earthquake, it is both.

Dr. Gottlieb said that when disaster strikes, those responding often turn to NLM first. Whether we make this a priority or not, people will continue to turn to NLM for reliable information.

Ms. Humphreys said that, in reviewing NLM activities, the issue is what kind of information resources that relate to medicine and health do people need when they are responding to disasters. Do those information resources already exist and can we make them available? Then there is the research and development aspect—some projects are specifically disaster-related and also general informatics research, as in the case of electronic health records. Sometimes the two come together, as in the case of a system of managing patient prescriptions during disasters, being tested by BHEPP. This isn't putting a librarian out on the front line during a chemical spill but more about introducing responders to our excellent resources and how to use them.

Ms. Arnesen said that NLM's strength is developing good tools and resources. Dr. Fleming said that NLM provides standardizing, not only of the need to get information to the site but also of the kinds of information that are being triaged to the regional areas. Dr. Ball added that the Regional Medical Libraries and NNLM play a critical role in disaster response, too.

Col. DeFrancis said we should make sure that NLM is not duplicating what FEMA is being doing. Ms. Humphreys acknowledged that point and said NLM is always mindful of it. In closing, she asked the Board to accept the Working Group report and revisit the topic later.

XV. REPORT FROM THE SUBCOMMITTEE ON OUTREACH AND PUBLIC INFORMATION

Chair Mary Ryan recapped yesterday's meeting, noting that Dr. Becky Williams gave an overview of the refreshed ClinicalTrials.gov Web site. Undertaken to enhance usability and incorporate new resources, this is the first step in a multiphase process to upgrade the site. Information is now organized for specific categories of users: patients, researchers and those who manage clinical trials. The search box is now more prominent, new features give users additional support, the glossary content has been updated, usage stats have been included and it's easier to find studies which are currently recruiting new participants. ClinicalTrials.gov currently has 95 million page views and 60,000 unique visitors every month. Committee member Dr. Marion Ball suggested NLM place short articles about the site in journals that physicians read including *Healthcare Informatics* and *MD Computing*, as well as publicizing the new site to the public. NLM Communications Director Kathy Cravedi suggested a collaboration with the National Health Council, which represents voluntary organizations like the American Heart Association and others, to inform their members about the site and solicit their comments. The group was helpful in the initial launch of ClinicalTrials.gov. Another natural outlet would be the National Network of Libraries of Medicine, which could alert its member libraries and those they serve.

Anna Tatro from the University of Maryland at Baltimore, Health Sciences and Human Services Library then spoke about an NLM-funded community health and advocacy program for high school students, Project SHARE (Student Health Advocates Redefining Empowerment). Twelve students from a local health academy high school were chosen for this after-school program. Its goals are: to empower students as health advocates for other students and for their parents; to help to reduce health disparities; and to create a curriculum which can be easily replicated elsewhere. The 154-hour curriculum includes classes in genetics, social determinants of health, health literacy, and navigating the healthcare system, among others. Among other skills, the students learn is how to write advocacy letters, make posters and give presentations. The program has had a modest number of students so far but seems very beneficial to those who have taken part. They are seeking additional funding to continue the program.

Next, SIS's Janice Kelly reported on GeneEd, a new Web site of genetics information for K-12. GeneEd is a collaboration of National Association of Biology Teachers, as well as NCBI and the National Human Genome Research Institute. Ms. Kelly also discussed other SIS sites that might interest students and teachers, including ToxMystery and Tox Town. Some of the suggestions that the Committee made were enlisting the FNLM to promote GeneEd, giving information about it and related sites to the press, working with school librarians, and giving information about the site to the NN/LM staff, since they provide information to K-12 students, too.

Discussion followed. Board members asked whether there should be an effort to get word about ClinicalTrials.gov to a broader audience. The site is heavily used, Ms. Humphreys reported, and many physicians know about it, but there are always more people to reach.

Would a perspective piece in the *New England Journal of Medicine* or some other widely read journal help introduce more people to ClinicalTrials.gov?

The International Committee of Medical Journal Editors has been instrumental in promoting the registration of clinical trials, said Ms. Humphreys. Actually, there are recurring editorials and comments in the *New England Journal of Medicine* about ClinicalTrials.gov, but focused more on the importance of transparency and the management of scientific research.

Revisiting GeneEd, Ms. Yokote asked about how to influence the schools of education? Those are the places to reach future teachers, who will develop future curricula.

Would it help with recruiting for SHARE if they expanded the program's scope to talk about health careers, Dr. Roskies asked. The students may be under-informed about such possibilities and might be very interested. Yes, Ms. Ryan replied, SHARE does cover health careers and has information about health careers on its Web site.

NLM Deputy Director for Research and Education Dr. Milton Corn commented on Dr. Fleming's question about ClinicalTrials.gov: Are physicians using it? NLM tries to measure their use of many of our information sources, but the landscape has evolved so quickly over the last decade that we really don't know. It's a critical issue, Dr. Mitchell concurred. Up-to-date is what they're using. And, clearly, we need to look to apps.

XVI. WEB HARVESTING PILOT PROJECT ON DOCTOR AND PATIENT BLOGS

Jennifer Marill, chief of the Technical Services Division, asked, Why would NLM want to collect Web-based content? What does it mean to collect the Web? What are the challenges associated with the work? Who else is engaged in this effort? She showed a brief video about the nature of today electronic communications, which, if not collected and preserved, could constitute a great gap in knowledge about medicine and health in the 21st century.

NLM has a mandate to collect, preserve and provide access to scholarly biomedical literature, irrespective of format. Collecting documents and pages from the Web is simply an extension of our mandate to collect a variety of print materials. As more information is issued only in electronic form, we need to use automatic mechanisms to collect content that falls within our collecting policies.

The NLM Collection Development Manual states that NLM attempts to aggregate and to maintain for permanent access, library materials that (1) record progress in research and biomedicine and the related areas of the life sciences, (2) document practice and teaching of medicine broadly defined, (3) demonstrate how health services are organized, delivered and financed, (4) chronicle the development and implementation of policy that affects research and the delivery of health services and (5) illustrate the public perception of medical practice and public health. It is this last point that specifically speaks to the importance of collecting examples of doctor and patient blogs.

Born digital materials reflect the record of scholarship and historical perspectives. They also reflect changes in society and technology. One can envision many opportunities if these

materials are preserved. The collections can offer greater diversity than traditional collections and, perhaps most key, the collections can be data mined in ways that our print collections cannot be. Newer search engines, tools and computational methods will allow scholars to find patterns to determine relationships, categorize documents and extract information from these corpuses. Most recently, for example, researchers have used analytical and computational tools to mine large datasets and Websites to reveal the spread of disease, public reaction and response to outbreaks.

So what do we mean, harvesting or collecting the Web? We want to be able to capture as much of the web site as desired, preserving the look and feel at the time that the site was captured. We expect to use defined, international standards to preserve the original form of the retrieved content, without modification. We want to programmatically collect metadata about the conditions of the capture process so we have a record of when and how the site was captured.

There are challenges to this activity. Web sites typically undergo continuous transformation. Web pages of interest disappear or links go bad before content can actually be acquired.

So what does a collection of webpages actually look like? The Internet Archive, a nonprofit organization, based in San Francisco California, has been archiving the Web since 1996. Many of you have probably used their Wayback Machine to view previous snapshots of Web sites and to find resources no longer available on the live Web. Ms. Marill showed several examples.

Discussing other institutions involved in this work, she cited the Library of Congress, which quickly grasped the significance of Web information during the 9/11 event and marshaled resources to collect as much Web content around the attacks and their aftermath as possible. Under a UK Web archiving effort, the World Wellcome Trust has been archiving its own Web site since 2004. There's also the 2005 Hurricane Katrina collection, an effort of the Library of Congress, the Internet Archive and others.

The International Internet Preservation Consortium (IIPC) was formed in 2003 to enable better cooperation and standardization of tools and techniques. An important aspect of this Web harvesting work, noted Ms. Marill, is to maintain familiarity with tools and developments that capture a variety of Web content.

Christie Moffatt, manager for the Digital Manuscript Program of the History of Medicine Division, spoke next about NLM's pilot project. Over the course of this past year, the NLM Web Collecting and Archiving Working Groups, including staff from LO, NICHSR and SIS, engaged in a pilot project to build a collection of doctor and patient blogs. The decision to focus on blogs resulted from the group's interest in the long-term historical value of these personal records. These blogs fit within NLM's collection policies for Electronic Resources, History of Medicine and selective acquisition of Popular Literature.

The blogs collected in the pilot project feature the perspectives of physicians, nurses, hospital administrators and other health professionals. Examples include the blog of "e-Patient Dave" deBronkart. He writes about patient empowerment and his experiences with cancer. Another is

Life as a Healthcare CIO, the blog of Dr. John Halamka, CEO of Beth Israel Medical Center, professor at Harvard Medical School and a practicing emergency physician.

During the pilot, NLM crawled selected blogs monthly for a year. To collect this content, they used the Internet Archives' Archive-It service, which provides the tools to harvest, manage and archive born-digital Web material. Challenges included robots.txt, basically a "please do not crawl" request that site creators can use to block Web crawlers from capturing pages. The biggest challenges included determining collection scope and gaining permissions.

The group has recommended that NLM use Web archiving to extend our traditional collecting capabilities to include born-digital Web information and to continue collecting. For example, HMD is currently collecting the papers of Dr. Tony Hunter of the Salk Institute. Using Web archiving tools, they can amass not only his scholarly works and notebooks, but also collect the Web site of his laboratory and his Facebook page. The working group also recommended that NLM participate in national collaborative efforts to preserve at risk web content like one in which NLM is already a participant, the Library of Congress led National Digital Stewardship Alliance (NDSA) whose mission is to establish, maintain and advance the capacity to preserve the nation's digital resources.

Ex-officio alternate member Kathryn Mendenhall from the Library of Congress referred to the fact that, at the time of Hurricane Katrina, NLM did not have a Web archiving program so it is good to see the progress in this area. How in the future will researchers know about these archived Web sites, she asked. Ms. Marill noted that NLM catalogues materials for the collection and is now planning to catalogue this particular collection of doctor and patient blogs once we do that that bibliographic record will be distributed of course through OCLC (Online Computer Library Center) and available to many other libraries. When Ms. Mendenhall asked the Board to assess the merits of these blogs, Col. DeFrancis said they would have tremendous value, showing possible gaps in counseling by physicians to their patients, on topics such as obesity. How do you assess the validity of some of these blogs, Col. Nace asked. Can that be done? Ms. Moffat said that NLM has been very selective and has received permission from the blog owners and we do see their credentials on their Web site.

It's tremendously important to capture these kinds of information, said Dr. Mitchell. This is a whole dimension of information that didn't exist 20 years ago. Her main concern is figuring out what is significant. How do you decide what to store and what not to store? There is so much and only in retrospect can you determine what's meaningful. There's an incredible amount of collaborative research that is going on which is not captured any more in those research notebooks; it's all digital. She said she's terribly happy that NLM is doing it.

Ms. Yokote asked whether there should be collaborative work to establish standards and divide the work. Ms. Marill noted there are lots of conversations going on in the national and international groups about who's covering what. Obviously as we provide metadata for some of these collections there will be an opportunity for librarians, for scholars to see what is out there and what is not yet being collected.

Returning to Dr. Nace's earlier point, Ms. Humphreys commented that NLM has a lot of interesting information in its collection that is now scientifically invalid, but fortunately that's not the information that is presented to the general public when they are searching for health information. In the same way, we are not going to send people with health questions to the blogs as a primary information source.

Dr. Fleming asked when, in the case of an exchange between a patient and health provider, when does this become a part of the medical record and when does HIPAA kick in? The physicians involved were given statements about protecting the privacy of their patients, Ms. Moffatt answered. Also there is a code of ethics going around for bloggers who are physicians. They are accepting the responsibilities that they have as physicians to the patients.

Board consultant Dr. Tenley Albright pronounced this another example of NLM thinking ahead and very broadly. In the case of collecting materials relating to Dr. Hunter, how much is enough, or too much? Her other thing is time capsules. In time capsules, we assumed that whatever was there would be interpretable later but, with the rapidly changing data formats, what would be the common denominator and how do we stay with it?

Ms. Humphreys said NLM cannot collect all the personal papers of all the scientists and medical people that are relevant historically, nor can it have a comprehensive collection of patient narratives. But, having samples that allow people to go back in time and view what it was like is essential and important.

Ensuring that whatever we do collect is accessible into the future is an important issue for NLM. If we are going to add anything to the collection, then we have to have a plan to migrate it forward as technology changes. There's no point in capturing it if 15 years from now it is no longer usable.

Dr. Corn approved of the project but commented about its ethics. NLM is funding a study by John Holmes at the University of Pennsylvania to see if he can use publicly accessible data without privacy rules. What did his internal review board (IRB) say? How ethical is it to repurpose information that somebody put out there even if it's legally safe to do so?

We just have to keep asking the question: how are we using and deploying information, and how might it impact other people, said Dr. Fleming. There's such an explosion in the types of information and how it is getting disseminated. A physician's email to a patient is like anything that's said in that physician's office, and does become part of the patient's official record.

XVII. ADJOURNMENT

Noting that the last topic was the perfect topic on which to end, Dr. Mitchell adjourned the Board of Regents meeting at 11:45 a.m. on September 12, 2012.

September 11-12, 2012 – Board of Regents

ACTIONS TAKEN BY THE BOARD OF REGENTS:

- Approval of the May 8-9, 2012 Board Minutes
- Approval of the September 17-18, 2013 Future Meeting Dates
- Approval of Change in Grant Operating Procedures for Special Council Review

Appendix A - Roster - Board of Regents

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

Betsy Humphreys
Deputy Director, National Library of Medicine

Joyce A. Mitchell, Ph.D.
Chair, NLM Board of Regents