The Context

NLM has the opportunity to play a critical role during an unprecedented era in biomedical research...
The Context

- Data science is expanding rapidly
- Computational power is increasing
- Breadth/depth of digital health data undergoing unprecedented and accelerating growth
The Context

• Movement towards more interdisciplinary work and team science

• Broad commitment to open science is becoming increasingly adopted

• Demand for services to support informed public expanding
NLM leadership:
Don Lindberg retired after 35 yrs of remarkable leadership;
Appointed in 1984!
Today’s Focus

• Report live today

• Can be found at http://acd.od.nih.gov/meetings.htm
Biomedical information research services and data science are critical to the future of medicine and health. Strategic recommendations for the National Library of Medicine (NLM) include maximizing resources, supporting programmatic efforts, and ensuring NLMs work with future leaders to advance biomedical research and informatics. NIH leadership and the Director are key in developing a vision for the organization's role in the broader scientific and medical community.
Charge to the NLM Working Group

• Review the current mission, organization, and programmatic priorities of the NLM

• Articulate a strategic vision for the NLM to ensure that it remains an international leader in biomedical and health information
Charge: Assess How NLM Should

• Continue to meet biomedical community’s rapidly evolving scientific & technological needs

• Lead the development and adoption of information technologies

• Facilitate the collection, storage, and use of biomedical data by the biomedical and health research communities
Charge: Assess How NLM Should

- Continue to lead in promoting open access models for biomedical data and scientific literature
- Balance computational methods and human-based approaches for indexing
- Maximize utilization and cost-efficiency of the NLM’s National Network of Libraries of Medicine
Charge: Assess How NLM Should

• Maximize the usefulness of the NLM’s other outreach and exhibits programs in the context of future opportunities

• Interface effectively with the broader and expanding NIH efforts in data science

• Directly contribute to addressing the major data science challenges facing the biomedical research enterprise
NLM Working Group Membership

Eric Green, NIH (co-chair)
Harlan Krumholz, Yale (co-chair)
Russ Altman, Stanford
Howard Bauchner, JAMA
Deborah Brooks, MJF Foundation
Doug Fridsma, AMIA
Steven Goodman, Stanford
Eric Horvitz, Microsoft Research
Trudy MacKay, NC State U
Alexa McCray, Harvard
Chris Shaffer, OHSU
David Van Essen, Wash U
Joanne Waldstreicher, J&J
James Williams, II, U Colorado, Boulder

EX OFFICIO MEMBERS
Kathy Hudson, NIH

EXECUTIVE SECRETARY
Lyric Jorgenson, NIH
Deliberative (and Rapid) Process

- Launched in January, 2015
- Met via 4 conference calls and 2 in-person meetings
  - Reviewed mission, organization, and programs
  - Met with NIH and NLM leadership
  - Evaluated NLM’s strengths and weaknesses
  - Identified emerging opportunities and challenges
Listen and Learn from Community

• RFI to listen to the broader community
  – 650 responses to 5 different areas of inquiry
OBSERVATIONS

“The remarkable work of NLM has generated international goodwill and reflected positively on the NIH and the United States. In fact, for many, NLM is the most visible face of NIH.”
Given the breadth of functions and activities, it is not surprising that NLM has many stakeholders – many of whom express resounding support for its mission.
What We Heard...

• Sharing quality health information to the public (easily and freely)

• Critical partner in advancement of library science innovation and established expertise and leadership in the collection, organization, curation, dissemination of biomedical data
What We Heard...

• Relied upon for many programs and resources including health information, data services, and training programs, ... such as...
Resources
Observations: NLM has Challenges

• Broad range of users creates diverse needs for NLM programs and tools

• Integration of programs into a coherent, forward-looking framework
Observations: NLM has Challenges

• Rapid expansion of the field of data science and biomedical informatics in the face of ongoing budget constraints

• Definition of role in broader NIH efforts
RECOMMENDATIONS

“NLM’s path forward must build upon its prior successes, leverage existing strengths, and capitalize on emerging opportunities.”
Recommendation #1: ‘General Scope’

NLM must continually evolve to remain a leader in assimilating and disseminating accessible and authoritative biomedical research findings and trusted health information to the public, healthcare professionals, and researchers across the world.
Recommendation #1: ‘General Scope’

• Coordinate with others on the collection, interpretation, and access of biomedical and healthcare-related information... and iterative process of resource creation, maintenance, and evaluation

• Connect disparate data sources and streams to enable improved knowledge integration and generation
Recommendation #1: ‘General Scope’

• Understand, integrate, and leverage the complementarity of its resources and services with the access and availability of biomedical and health information via search engines and browsing of other sources of health information on the Internet
Recommendation #1: ‘General Scope’

“NLM should also play a leadership role in harmonizing, connecting and improving international databases...”
Recommendation #1: ‘General Scope’

“...For example, one could envision a future in which ClinicalTrials.gov plays a key role in the global harmonization of requirements and standards, while also expanding in scope to accommodate hosting of metadata and even participant level data.”
Recommendation #2: ‘Open Science’

NLM should lead efforts to support and catalyze open science, data sharing, and research reproducibility, striving to promote the concept that biomedical information and its transparent analysis are public goods.
Recommendation #2: ‘Open Science’

• Serve as locus of expertise for managing and evaluating NIH databases and knowledge bases

• Engage in bioethical considerations of sharing biomedical data
Recommendation #2: ‘Open Science’

- Promulgate and implement best practices in open source, open science, standards, and data harmonization
- Collaborate with developer communities
“NLM should be an active participant in the design and oversight of programs that incentivize and celebrate the open sharing of data and resources.”
“Tools and resources should be disseminated using industry standards for data sharing and programmatic access (e.g. well documented APIs or SPARQL endpoints) to enable reuse by researchers and other stakeholders.”
Recommendation #3: ‘Data Science’

NLM should be the intellectual and programmatic epicenter for data science at NIH and stimulate its advancement throughout biomedical research and application.
Recommendation #3: ‘Data Science’

• Become programmatic and administrative home for the BD2K Initiative and take lead in defining subsequent data science efforts; coordinate data science programs across ICs
Recommendation #3: ‘Data Science’

- Promulgate intramural and/or extramural expertise, knowledge generation and dissemination, and leadership in areas of data science that are critical to the NIH mission
“NLM should lead the coordination of data science programs (and programs with large data science components) conducted at other NIH Institutes/Centers, in order to maximize synergies and minimize redundancies.”
Recommendation #3: ‘Data Science’

“...nurture talent in the science and engineering of EHRs, analysis of biomedical text, integration of diverse and multimodal datasets, application of novel computational and statistical methods to extract knowledge, and future domains that involve extracting data and producing knowledge from digital health sources.”
Recommendation #4: ‘Training’

NLM should strengthen its role in fostering the future generation of professionals in biomedical informatics, data science, library sciences, and related disciplines through sustained and focused training efforts.
Recommendation #4: ‘Training’

- Develop and support new, comprehensive, and coordinated strategic training initiatives related to professional development across multiple spheres

- Be center for nurturing the core science and methodologies of biomedical informatics, data science, and library science through research and training programs
Recommendation #4: ‘Training’

“...also nurture partnerships with other NIH programs, Federal agencies, and outside organizations in which informatics and biostatistics are a core component.”
Recommendation #5: ‘History’

NLM should maintain, preserve, and make accessible the nation’s historical efforts in advancing biomedical research and medicine, thereby ensuring that this legacy is both safe and accessible for long-term use.
Recommendation #5: ‘History’

• Lead and form partnerships to advance the core professional domains of data and knowledge capture

• Develop and implement a strategic preservation and access plan for medical knowledge in all formats
Recommendation #5: ‘History’

*All formats includes ephemeral forms that are increasingly dominating medical communication (e.g., online journals, blogs, and databases)
Recommendation #6: ‘Further Evaluation’

New NLM leadership should evaluate what talent, resources, and organizational structures are required to ensure NLM can fully achieve its mission and best allocate its resources.
Recommendation #6: ‘Further Evaluation’

- Evaluate the current NLM portfolio of databases, resources, and services
- Review and potentially reorganize the structure and functions of NLM to ensure that they align with the contemporary vision and mission
“NLM has the opportunity to modernize the conceptualization of a library.”
A Robust NLM is Vital

• NLM has an exemplary history of excellence, both in terms of accomplishments and world-wide reputation in the research and health sciences communities
A Robust NLM is Vital

• NLM must now evolve to seize this critical moment in biomedical history and be a trustworthy source of biomedical data and information, an advocate for open science, a promoter of the next generation of data scientists, a protector of the legacy of the past, and a vital partner for those generating biomedical knowledge for future
Questions?

http://acd.od.nih.gov/meetings.htm