ADVISORY COMMITTEE TO THE NIH DIRECTOR

National Library of Medicine Working Group – Interim Briefing about the Final Report

Harlan M. Krumholz

Co-Chair, NLM Working Group

ACD Meeting – June 11, 2014

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

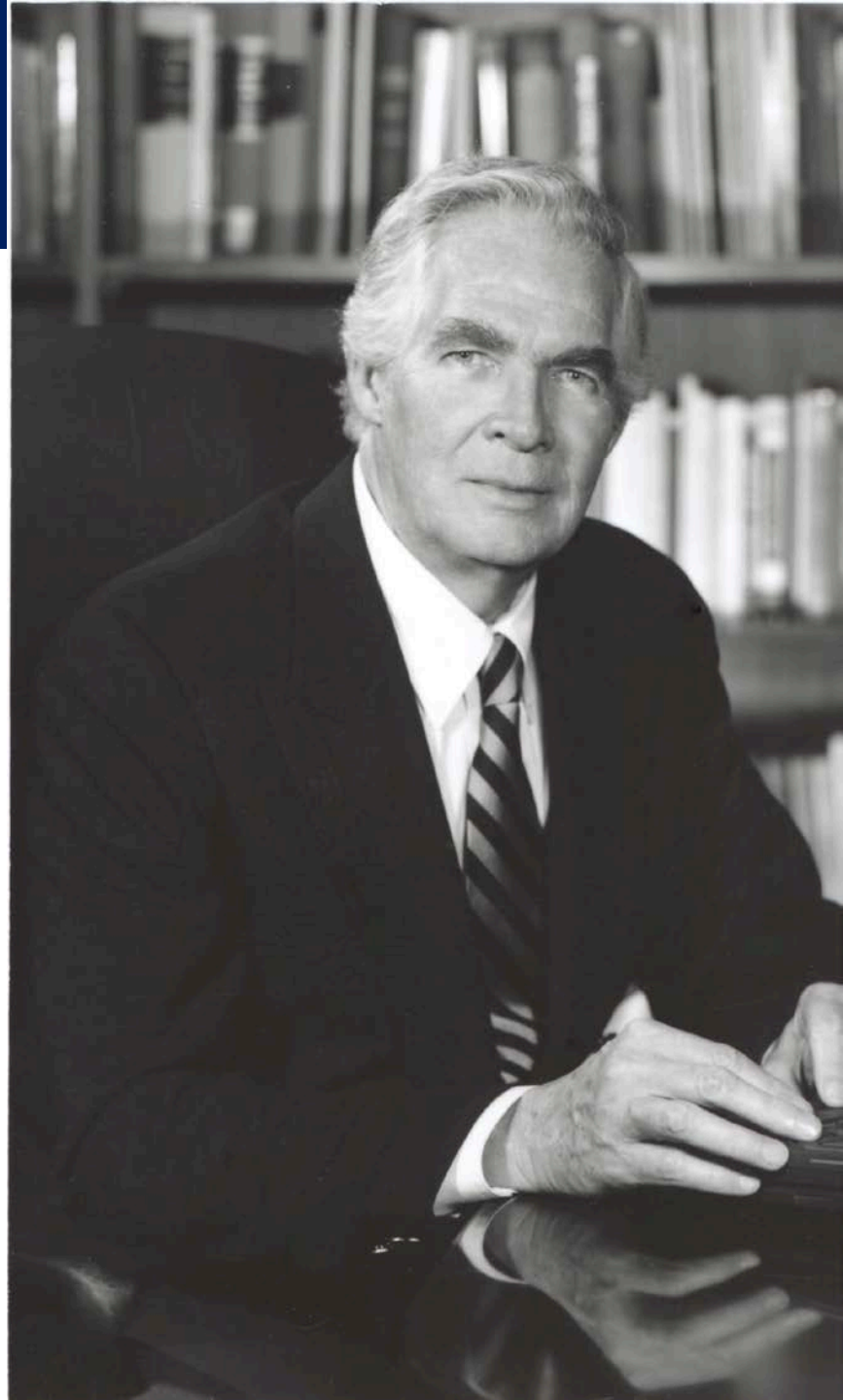
- Movement towards more interdisciplinary work and team science
- Broad commitment to open science is becoming increasingly adopted
- Demand for services to support informed public expanding

The Context *(cont.)*

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

National Institutes of Health

Advisory Committee to the Director

National Library of Medicine (NLM) Working Group

FINAL REPORT – JUNE 11, 2015

MEMBERS: Eric Green (co-chair), Harlan Krumholz (co-chair), Russ Altman, Howard Bauchner, Deborah Brooks, Doug Fridsma, Steven Goodman, Eric Horvitz, Trudy MacKay, Alexa McCray, Chris Shaffer, David Van Essen, Joanne Waldstreicher, James Williams, II, Kathy Hudson (ex officio), Lyric Jorgenson (executive secretary) *(titles and affiliations listed in Appendix A)*

EXECUTIVE SUMMARY

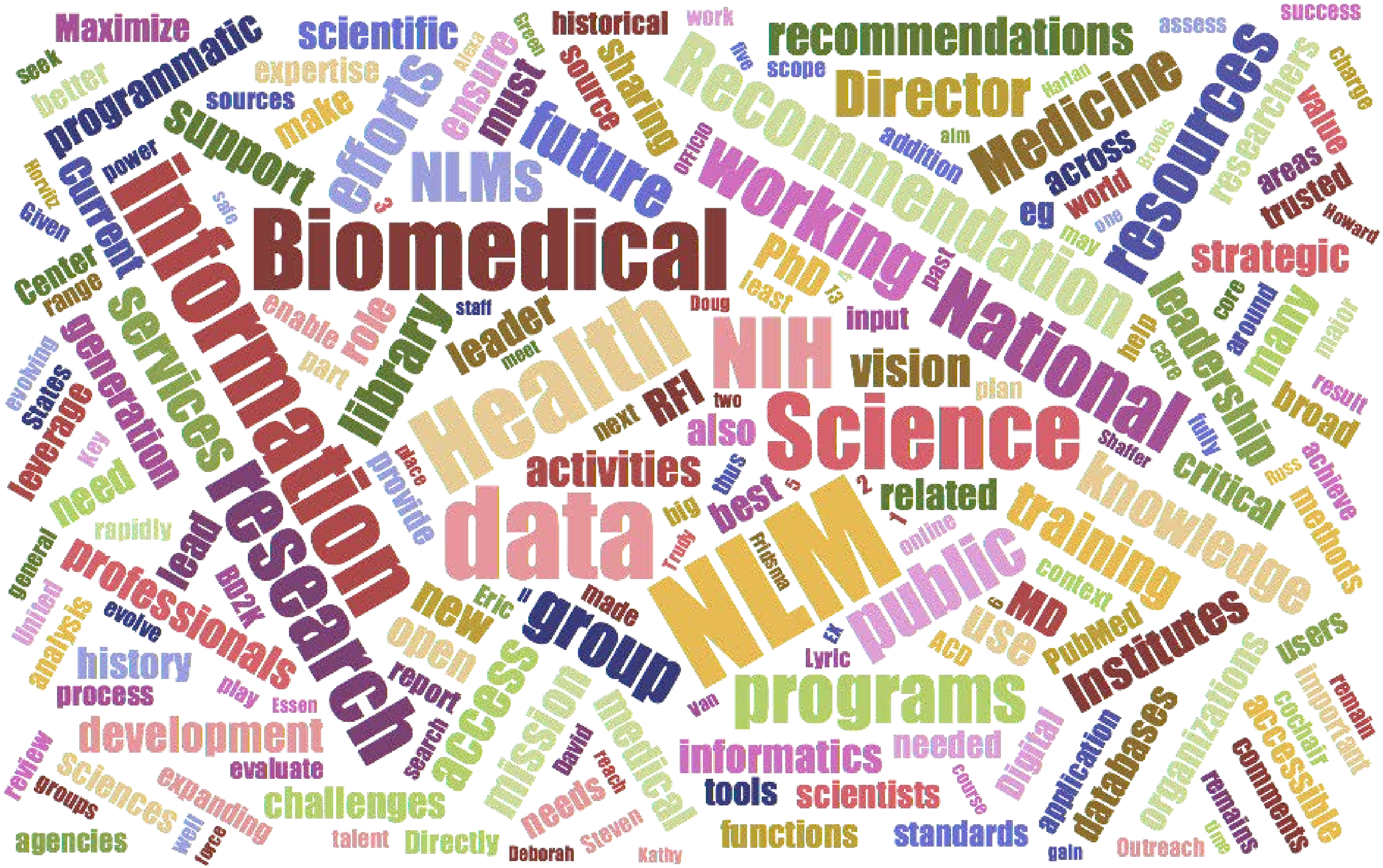
The NIH Director charged the National Library of Medicine (NLM) Working Group, hereafter referred to as the Working Group, with articulating a strategic vision for NLM to ensure that NLM remains an international leader in biomedical and health information. Over the course of five months of deliberations, the Working Group reviewed numerous documents and reports pertaining to NLM's mission and activities, consulted with NLM leadership and staff, and solicited public comments and suggestions. The Working Group recognizes that NLM has an important opportunity to play a key leadership role in one of the most exciting periods of biomedical history: data science is increasing rapidly, computational power is expanding at a breathtaking pace, the breadth and depth of digital health data are undergoing unprecedented and accelerating growth, a movement towards more interdisciplinary work and team science continues to gain momentum, a broad commitment to open science is becoming increasingly adopted, and the demand for services to support an ever more engaged and informed public is expanding. To leverage these historic changes, the Working Group, with respect for the outstanding history of NLM and its potential for the future, formulated a series of recommendations to guide the future of NLM:

RECOMMENDATION #1. 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 worldwide.

RECOMMENDATION #2. 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 #3. NLM should be the intellectual and programmatic epicenter for data science at NIH and stimulate its advancement throughout biomedical research and application.

Report


Maximize
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Outreach
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Lyric
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Doug
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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."

Observations

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


ClinicalTrials.gov
A service of the U.S. National Institutes of Health

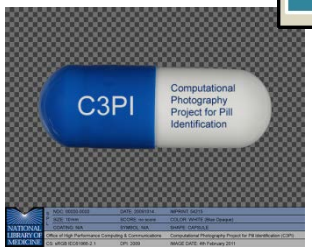

MEDLINE
U.S. National Library of Medicine


MEDLINEplus®
Health Information


PubChem

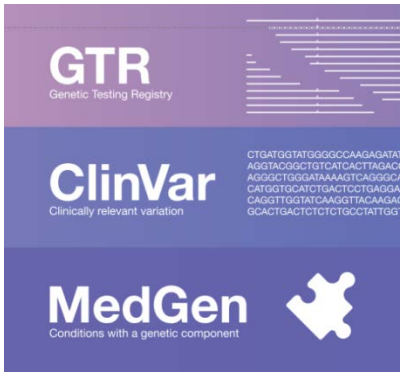

NN/LM
National Network of Libraries of Medicine


DOCLINE®
Interlibrary loan request routing and referral system
user name
password
login >>
DOCLINE Information
Login Help


C3PI
Computational Photography Project for Pill Identification

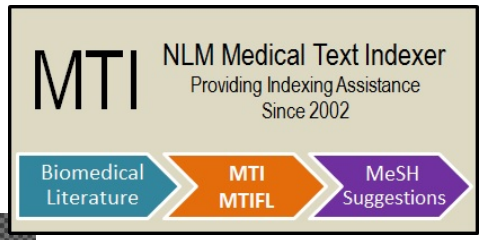

MeSH
MeSH on Demand


LiverTox
Clinical and Research Information on Drug-Induced Liver Injury


GTR
Genetic Testing Registry
ClinVar
Clinically relevant variation
MedGen
Conditions with a genetic component


Search
DRUG INFORMATION PORTAL


THE VISIBLE HUMAN PROJECT™
FROM THE NATIONAL LIBRARY OF MEDICINE


MTI
NLM Medical Text Indexer
Providing Indexing Assistance Since 2002
Biomedical Literature
MTI MTIFL
MeSH Suggestions


LHNCBC

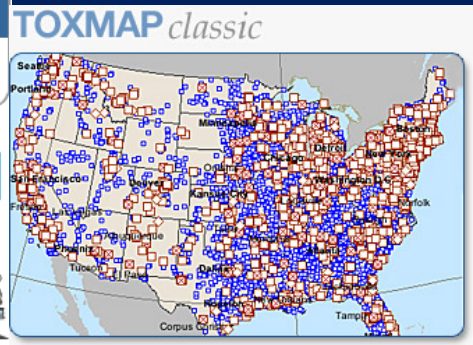

NCBI


Haz-Map
@NIH


db GaP
GENOTYPE and PHENOTYPE


NCBI
BLAST


OPEN
PubMed
WISER


TOXMAP classic


NIH U.S. National Library of Medicine
NLM Informatics Training Conference
2013
June 18-19
Salt Lake City, UT


Profiles in Science
National Library of Medicine


Conversations with Medical Informatics Pioneers
An Oral History Project
Q&A


NLM
TOXNET
Toxicology Data Network


Genetics Home Reference
Your Guide to Understanding Genetic Conditions


NATIVE VOICES
NATIVE PEOPLES' CONCEPTS OF HEALTH AND ILLNESS

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

Recommendation #2: ‘Open Science’

“NLM should be an active participant in the design and oversight of programs that incentivize and celebrate the open sharing of data and resources.”

Recommendation #2: ‘Open Science’

“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

Recommendation #3: ‘Data Science’

“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

CONCLUDING REMARKS

"NLM has the opportunity to modernize the conceptualization of a library."

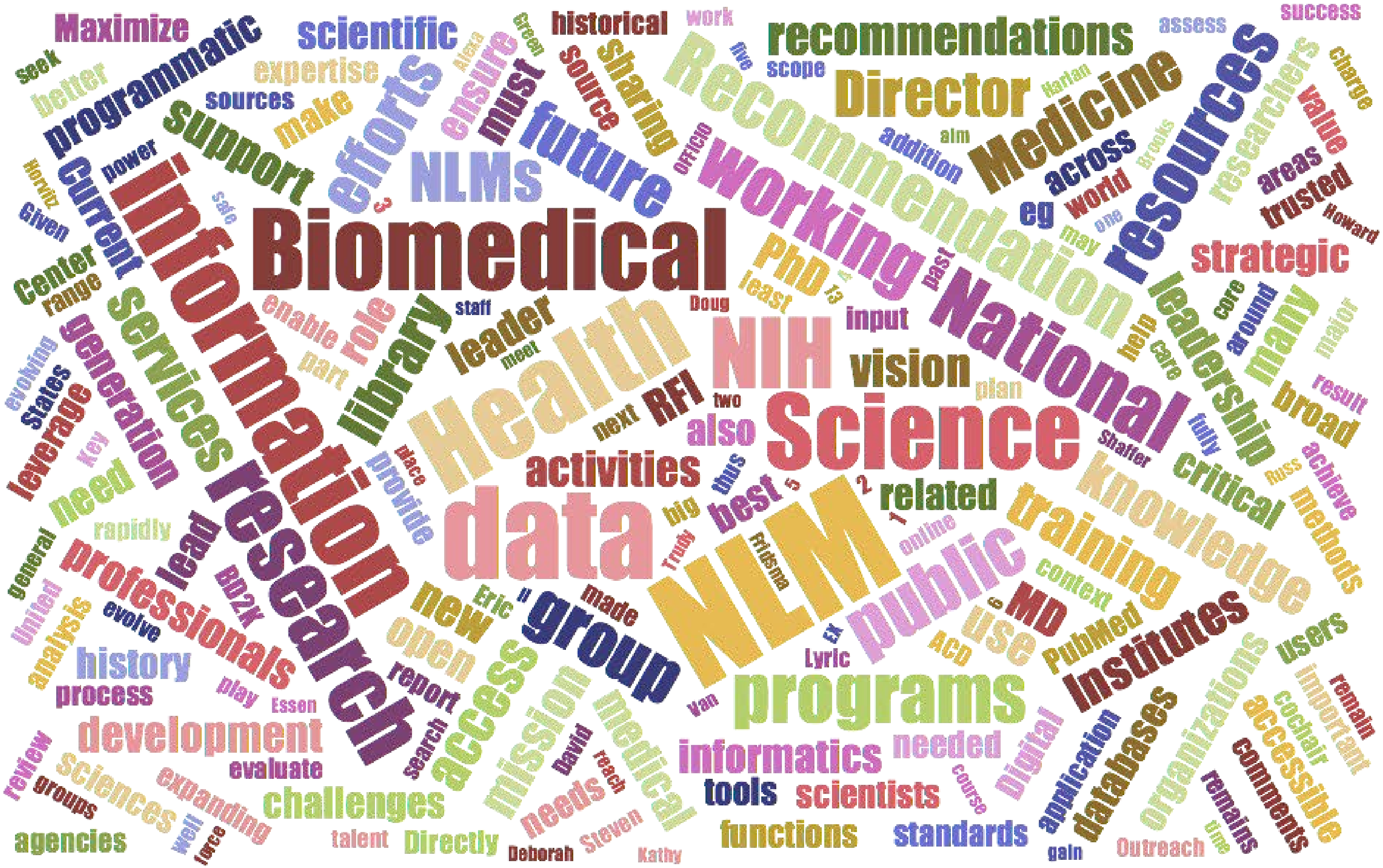
A Robust NLM is Vital

- 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