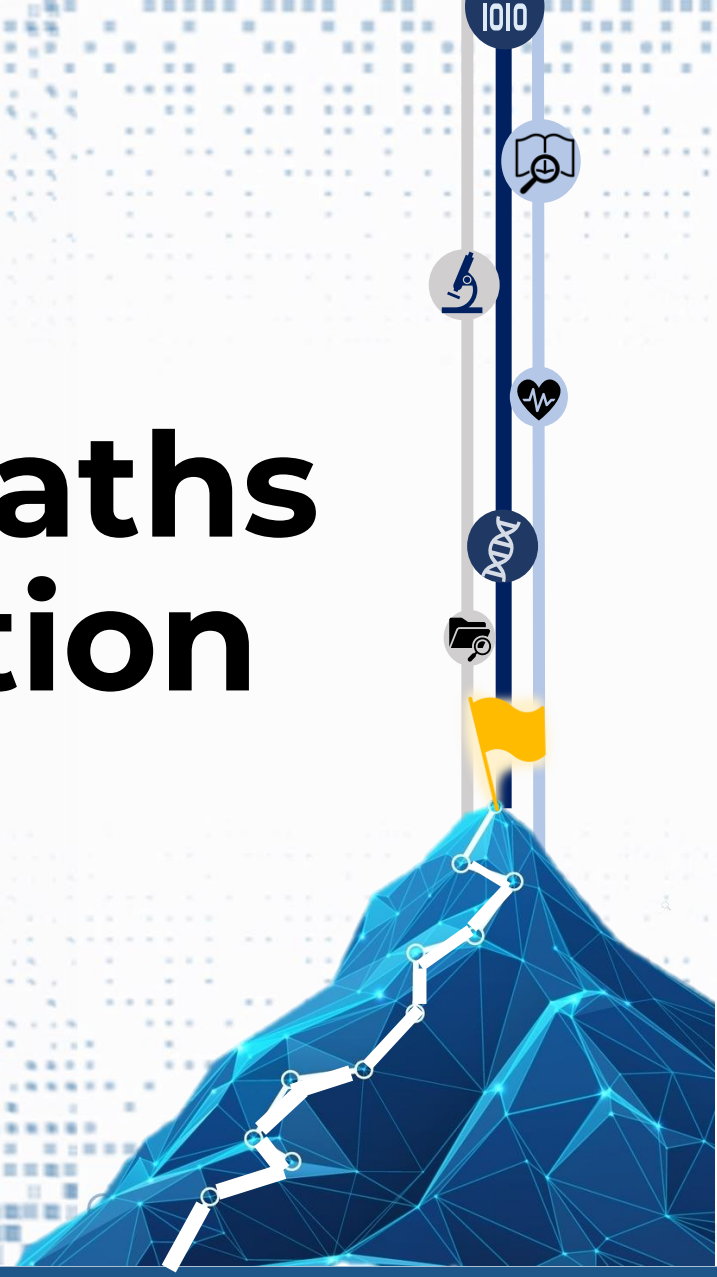
Discovering New Paths to Health Information

National Library of Medicine

MLA Conference

May 2024



Dianne Babski

Director,

User Services and Collection Division

Agenda

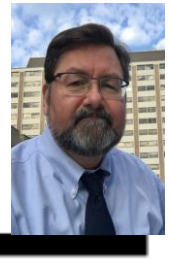
- Introduction
- Updates NLM
- Updates from NNLM
- Discussion

What is the National Library of Medicine?

17th NIH Director, Dr. Monica Bertagnolli

NLM Org Structure

Dr. Steve Sherry
Acting NLM Dir



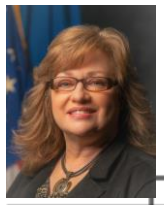
Office of the Director

Executive Office

Computer Technologies

Strategic Initiatives

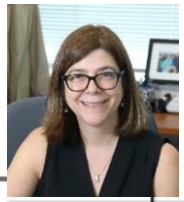
Communications



USCD

Extramural Research

LHC



NCBI

IRP

NLM Job Openings: https://hr.nih.gov/jobs/search/executive/job-87536

USAJobs: https://www.usajobs.gov/

Advice and Guidance from the Library Community

BoR Chair

Kristi Holmes, Ph.D.
Northwestern University

BoR Member

Phillip Walker, MS, MLIS
Vanderbilt University

BoR Member

Mary Mazanec, MD, JD
Library of Congress

BoR Member

Paul Wester, MLS
National Agricultural Library

LSTRC Member

Jonathan Eldredge, Ph.D.
University of New Mexico

BILDSRC Member

Charles Senteio, Ph.D., MBA, MSW
Rutgers University

NIH Videocast: https://videocast.nih.gov/

NLM Associate Fellows 2023 - 2024

Alex Henigman

Ariah Long

Kristi Torp

Julie Volpenhein

ALA/MLA/NLM Spectrum Scholars 2023 - 2024

Bernice Meja
University of North Carolina at Chapel Hill

Camryn "Cam" Burkins
University of Illinois – Urbana-Champaign

NLM Intramural Trainee Opportunities

Welcoming fellows in the NLM Data Science and Informatics Scholar Program

Musings from the Mezzanine:
https://nlmdirector.nlm.nih.gov/2024/05/15/the-secret-to-research-trainee-success-hands-on-and-real-world-experiences-through-nlm/

Strategic Plan & Vision

- Long Range Plan
- Reorganization from Library Operations (LO) to the User Services & Collection Division (USCD)

USCD Long Range Plan Goals

1

Goal 1: Create a Modernized Organizational Structure

- ✓ Reorganize into USCD Branches based on function

2

Goal 2: Unify Collections

- ✓ Documentation/ SOPs
- ✓ Analysis of workflows
- ✓ Assess workforce needs
- • Monitoring/ alignment of repository tools
- • Assess vendors, usage, and impact

3

Goal 3: Support and Promote the Use of Health Data Standards & Terminologies

- ✓ Establishment of the Health Data Standards Branch
- • Selection of Health Data Standards Technical Lead

4

Goal 4: Provide Customer Experience (CX) Support

- • Implementing CX strategy and roadmap recommendations

5

Goal 5: Know and Equitably Engage Our Users

- • Additional and enhanced collaboration opportunities with engagement staff
- • Innovative engagement methods

From LO to USCD – What We Do

Collect

Acquire and preserve unique and trusted collection of biomedical information

Curate

Make biomedical information findable through data normalization, metadata and data standards

Connect

Link our global audience to biomedical data and resources to make informed health decisions

USCD Overview

Mission

("What")

Collect, curate, and connect the world to scholarly biomedical literature, health information and data resources

Vision

("Impact")

Empower scientists and society to use credible, equitable, and accessible biomedical information to improve global health

USCD Branch Descriptions

Collections (Collect)

Selects, acquires, and preserves biomedical resources in all formats

Health Data Standards (Curate)

Develops, maintains, and distributes health data standards and terminologies products and services

Discovery (Curate)

Describes, indexes, and curates the NLM collections and other trusted health information, data, and resources

Engagement (Connect)

Provides access to and fosters engagement with NLM collections, data, standards, and resources

Division — User Services and Collection Division (USCD)

Office of the Director (OD)

Director of USCD – Dianne Babski
Deputy Director of USCD – Amanda Wilson
Senior Historian – Jeffrey Reznick
Senior Administrative Officer – Deborah Lockett-Jordan

NICHSR

LSTRC

Branches (4)

Branch Chief

Deputy Branch Chief

Programs (10)

Program Managers

Collection	Health Data Standards (HDS)	Discovery	Engagement
Margaret McGhee	TBD	Tina Shrader (Acting)	Stacey Arnesen
Beth Weston	TBD	Jennifer Diffin (Acting)	Ken Koyle
Collection Development Julie Silverman	**Controlled Vocabulary Services** Carlo Nuss (Acting)	**Data Applications & Systems** Jennifer Diffin	**Access** Terry Ahmed
Collection Management Laura Hartman (Acting)	**Terminology Services** Patrick McLaughlin	**Health Information** Lisa Mohammed	**User Engagement** Blair Anton
Digitization TBD		**Metadata Management** Barbara Bushman (Acting)	

Product & Services Update

- Dataset Tools
- Literature Products
- Collection Development

Overview: Dataset Catalog

PubMed of Datasets!!

WHAT

- A catalog of biomedical datasets from selected publicly available repositories.

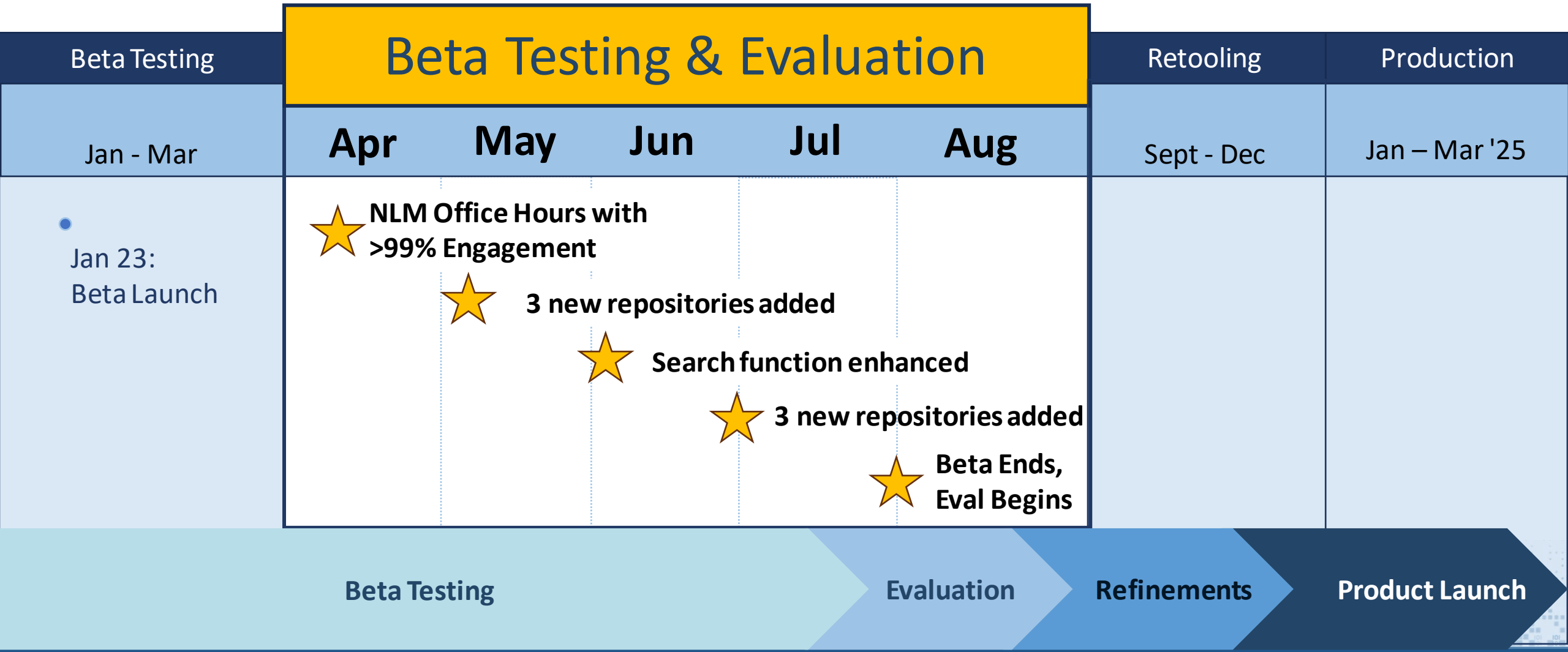
WHY

- Provide discovery systems for users, as stated in NIH Strategic Plan for Data Science and NLM 2017-2027 Strategic Plan.
- Allow researchers to discover biomedical datasets from many repositories.
- Drive adoption and acceptance of the NLM standard - DATaset Metadata Model (DATMM).

HOW

- Launch a beta version of Dataset Catalog using DATMM:
  - Assess Usage, Scalability and Sustainability of Dataset Catalog
  - Receiving user feedback to drive further development
  - Drive interest and adoption of DATMM

Dataset Catalog Timeline



Center for Clinical Observational Investigations (CCOI)

Clinical Datasets Concierge

RESEARCH NEEDS

Large clinical datasets are an essential resource for biomedical research as they can allow for greater strength and reliability in findings and may reduce the need for some traditional research trials.

CCOI MISSION

To reduce barriers to finding and evaluating for use relevant **clinical datasets** by providing a curated metadata profile.

CCOI Project Phases

Phase I: Data Curation and Needs Assessment (FY 24)

- Initial group of dataset profiles developed
- Semi-structured interviews with NIH intramural researchers of varying levels of experience and areas of research
- Incorporate feedback

Phase II: CCOI Dataset Profiles Enhancement (FY 24 & FY25)

- Introduce new functionalities (e.g., querying/filter, data visualization)
- Identify and curate dataset profiles for new datasets (e.g., rare diseases and health equity-related datasets)

Phase III: Evaluation & Future Planning (FY 25 & beyond)

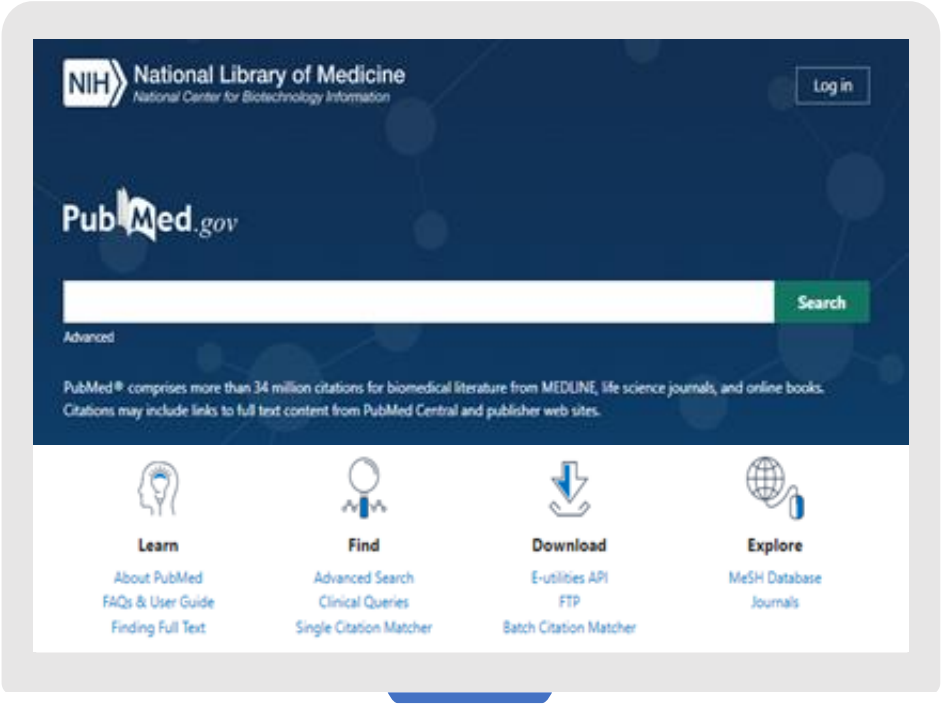
- Assess use of CCOI Dataset Profiles and continuously monitor feedback for future improvements
- Provide Data Science and Analytic services (NIH)

Dataset Catalog and CCOI Dataset Profiles

		Dataset Catalog	CCOI
Scope			
	Datasets	Original research datasets	General purpose data collected during the care process
	Domain	All research (including basic biological & animal research)	Clinical data
	Origin of dataset	Scientific research	EHR, claims, EMS
Functionality			
	Main value	Make datasets findable	In-depth characterization of datasets
	Goal	• Link to source website, • Data reuse • Accelerate scientific discovery	• Determine suitability to answer specific clinical questions, • Data reuse, • Improve clinical decisions and outcomes
	Additional Services	• Gradual addition of repositories • Improved search • Programmatic API endpoint	(Future) NIH Intramural assisted data analysis, statistical consultation, research partnership
	Size	76,826 datasets (5/15/2024), 5 repositories	4 international clinical datasets, ~384,000,000 cases spanning 70 years

PubMed Updates

- Proximity searching now available in the Affiliation field
- Wildcard searching
- New improved MEDLINE indexing algorithm - MTIX

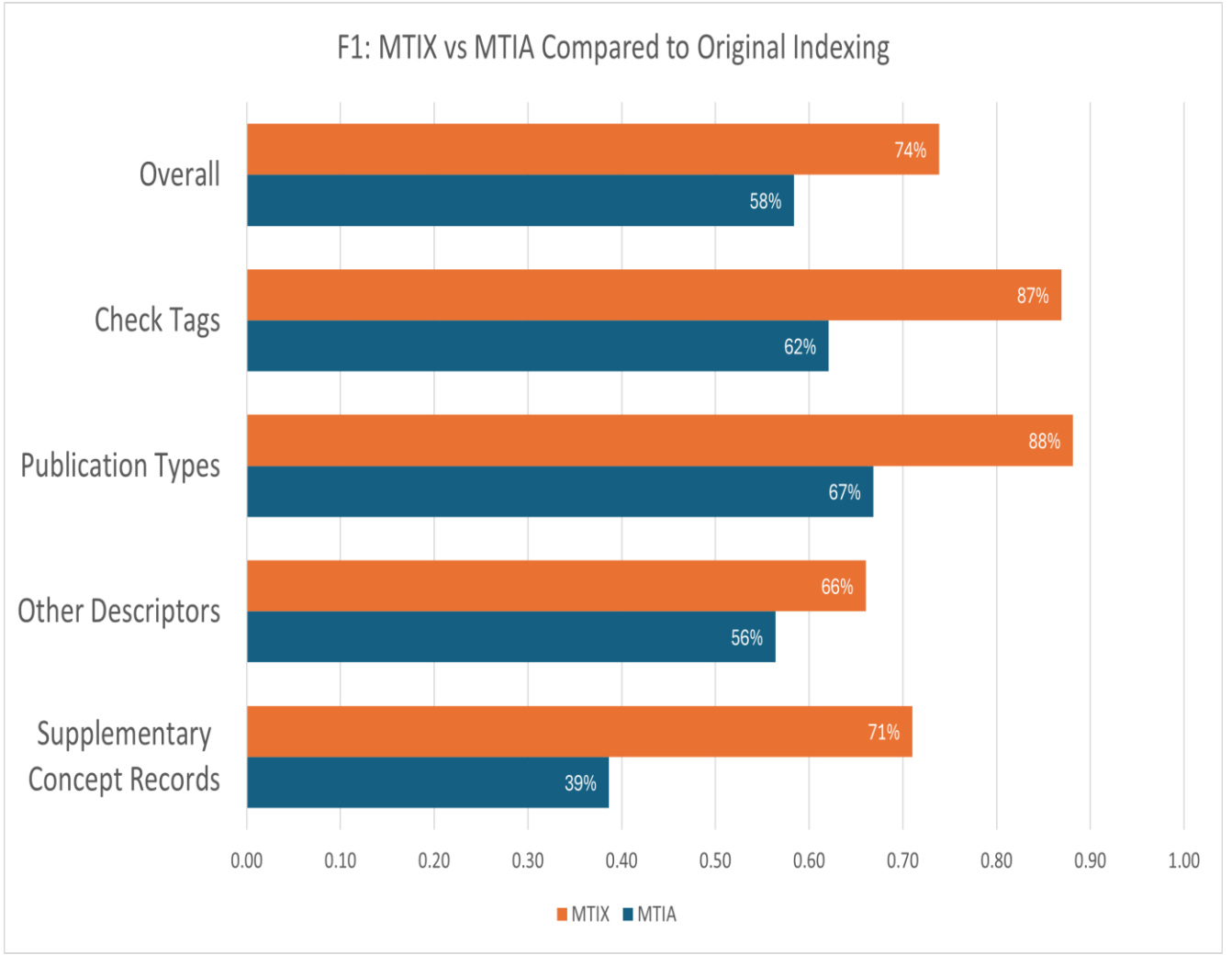


Please send us your feedback!

Write to the PubMed team via the NLM Help Desk: https://support.nlm.nih.gov/

PubMed Update

MTIX (Medical Text Indexer-NeXt Generation) for MEDLINE



PubMed Office Hours

June 11, 2024

1:00 PM – 2:00 PM EDT

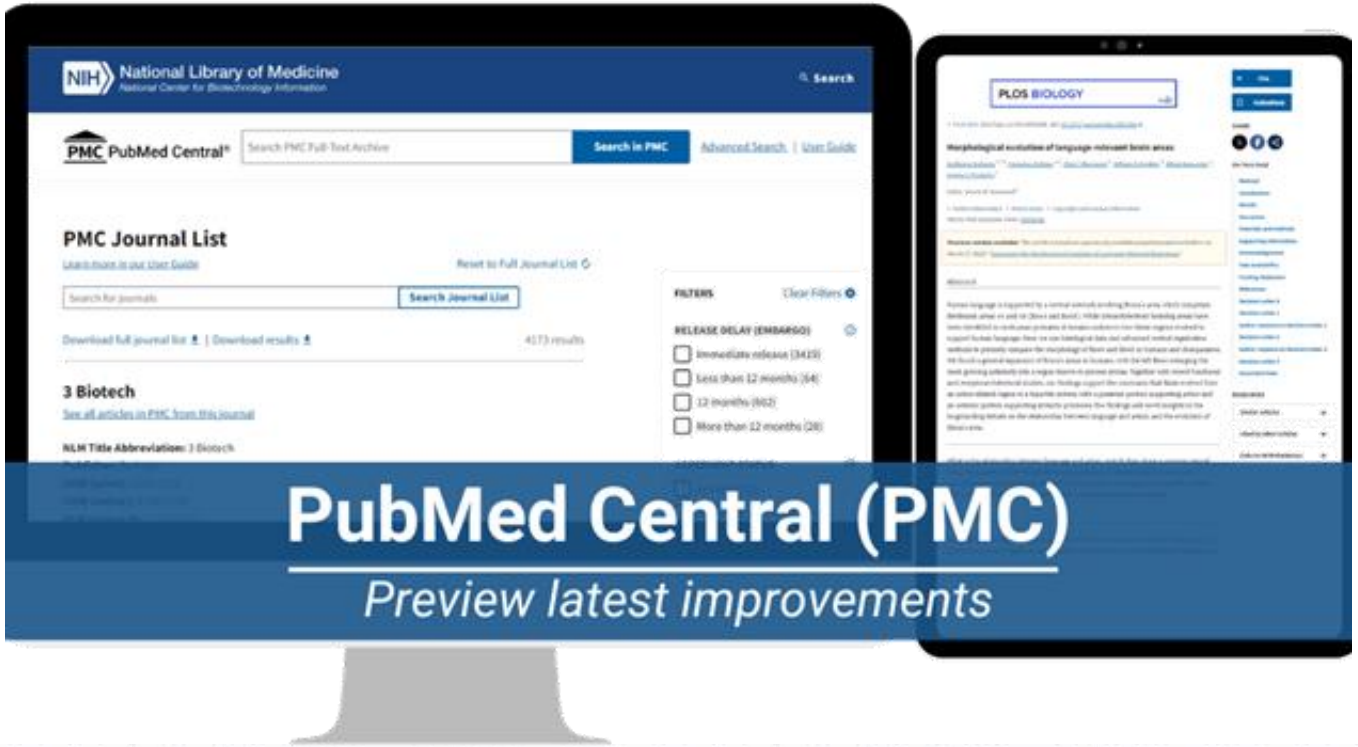
https://www.nnlm.gov/training/class/nlm-office-hours-pubmed-1

PubMed Central (PMC) Update

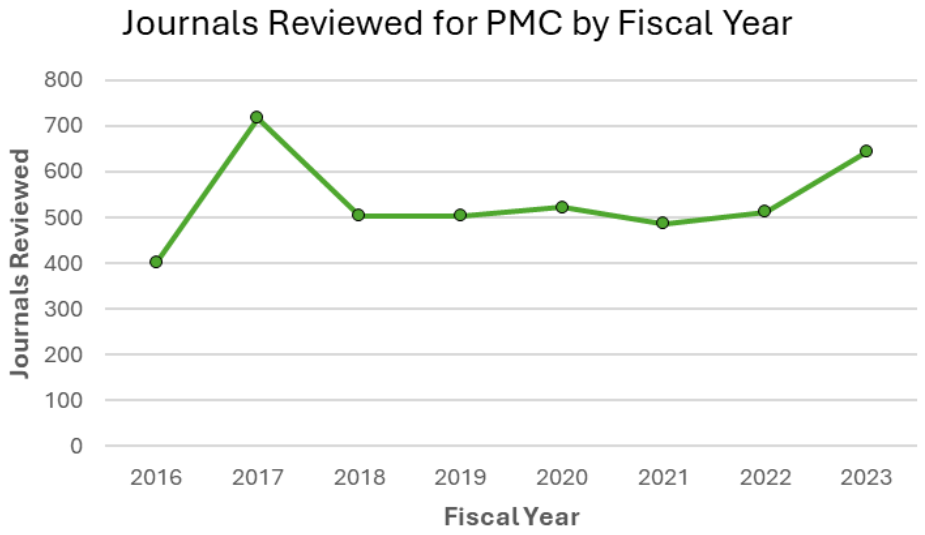
Preview updates to the PMC website rolling out in October 2024 – available now!

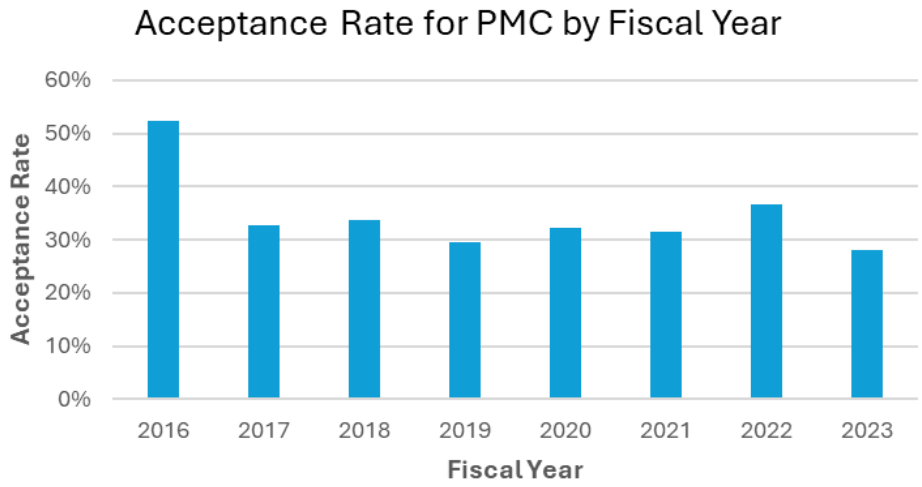
- Updated article display with easy-to-access navigation
- Reimagined PMC Journal List with filters

Send your feedback!



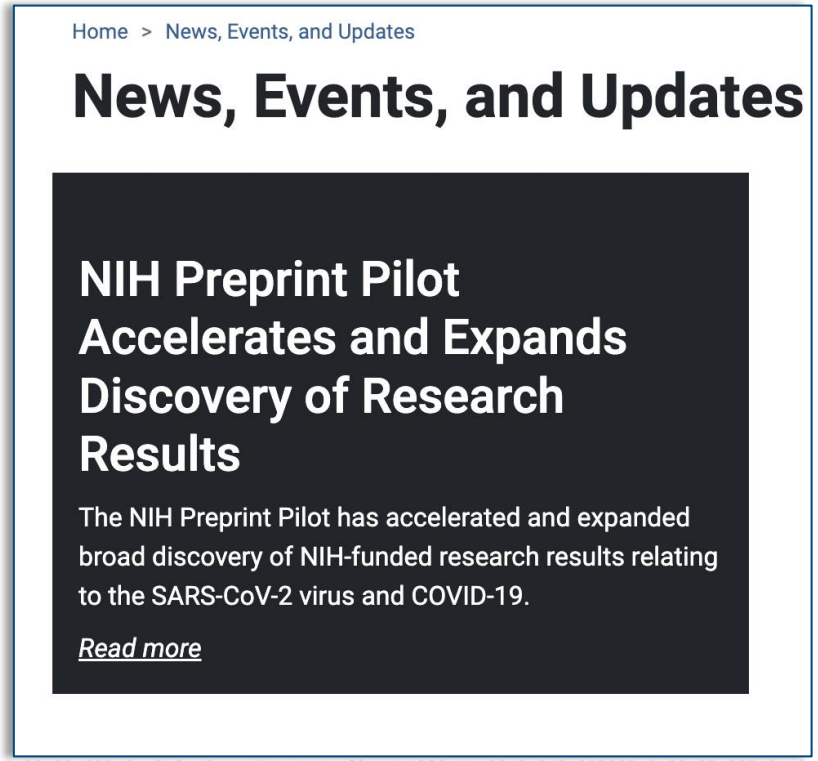
PMC Update


Journals Reviewed for PMC by Fiscal Year
800
700
600
500
400
300
200
100
0
Journals Reviewed
2016
2017
2018
2019
2020
2021
2022
2023
Fiscal Year


Acceptance Rate for PMC by Fiscal Year
60%
50%
40%
30%
20%
10%
0%
Acceptance Rate
2016
2017
2018
2019
2020
2021
2022
2023
Fiscal Year

PMC Update: NIH Preprint Pilot

- More than 20,000 NIH-supported preprints indexed to date
- Continue to monitor and assess the impact of this work on
  - discovery of NIH research
  - user trust
  - NLM workflows
  - author open science practices



ClinicalTrials.gov Modernization

Strategic Goals:

Improve the user experience

Upgrade the technical infrastructure and processes to enhance sustainability

Support the existing legal, regulatory, and policy framework

Vision:

Ensure ClinicalTrials.gov continues to be a trusted and valued premier public health resource that provides maximum value to the public and serves its mission well into the future.

ClinicalTrials.gov Modernization Timeline

YEAR 1
Initial Engagement Activities

- Engaged stakeholders to determine and validate approach and specifications
- Enhanced internal business processes
- Developed modernization roadmap

YEAR 2
Development

- Developed new product experiences
- **Launched first release of ClinicalTrials.gov Beta**
- Communicated availability of the beta release to stakeholders

YEAR 3
Implementation

- **Launched first release of Protocol Registration and Results System (PRS) Beta and released updates**
- Conducted usability research and made iterative improvements to the beta sites

YEAR 4
More Releases and Refinements

- Launched the modernized ClinicalTrials.gov website
- Released PRS Beta protocol registration

YEAR 5
Launches and Landings

Where we are now

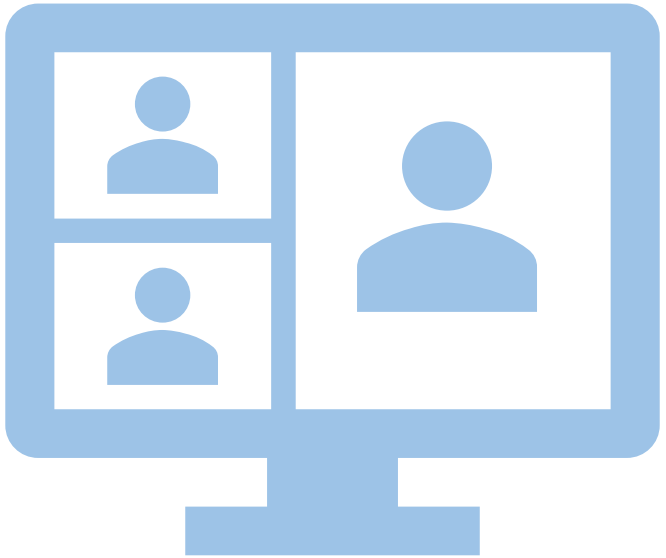
- Build and release the PRS Beta results reporting components
- Continue engagement, making updates and refinements
- **Retire Classic ClinicalTrials.gov June 25, 2024**
- **Launch the modernized PRS**

ClinicalTrials.gov Modernization Event

Free NLM Webinar:
Join us on June 6, 2024, at 1-1:45 p.m. ET.

ClinicalTrials.gov Staff will:

- Share an update on the overall modernization effort,
- Highlight features of the modernized website, and
- Help users prepare for the retirement of the classic ClinicalTrials.gov.



NIH Comparative Genomics Resource (CGR)

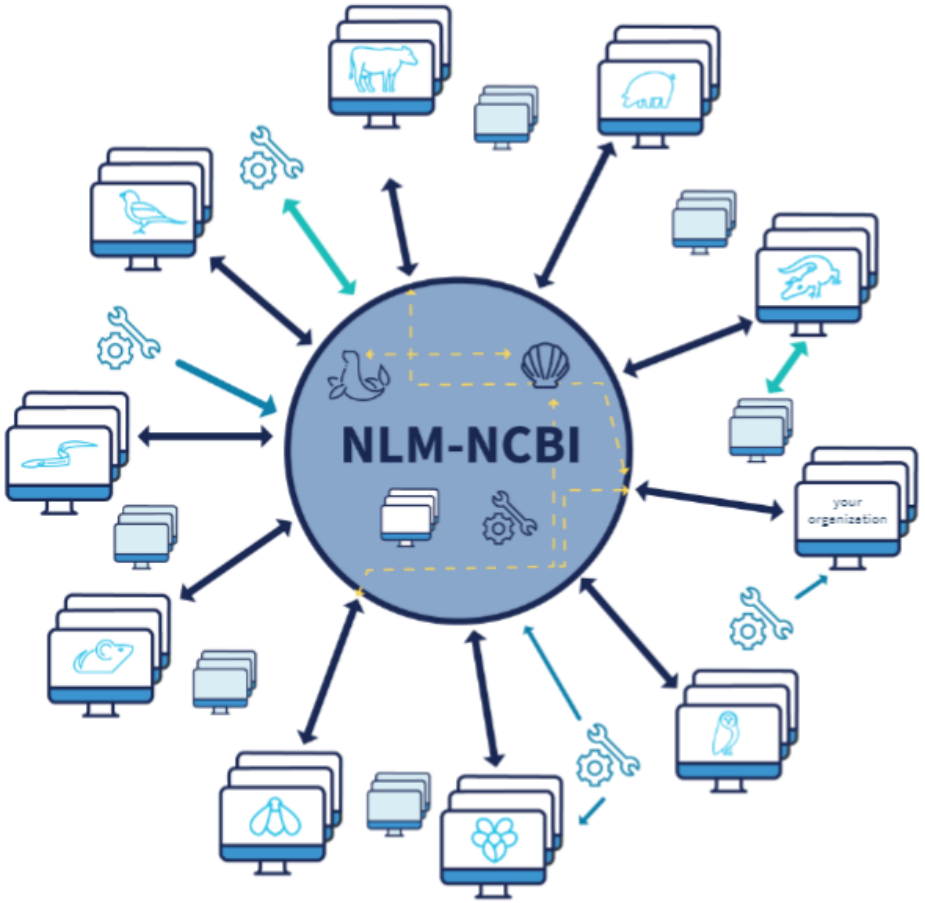
Maximize the impact of eukaryotic research orgar and their genomic data to biomedical research

CGR provides:

- ✓ High Quality Genomic Data
- ✓ New and Improved Comparative Genomics Tools
- ✓ Community Collaboration and Connection

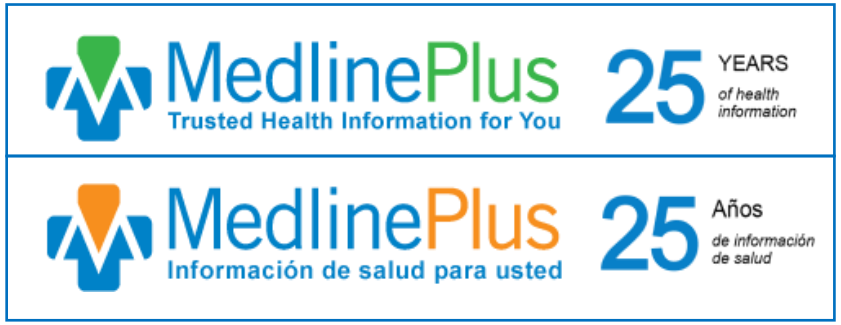
CGR enables:

- ✓ Scalable Analysis
- ✓ New Discovery Amplification
- ✓ Scientific Advancement



MedlinePlus Update

- Review and update of unique content
  - 100 Health Topic summaries
  - 100 Medical Test monographs
  - 140 Genetic Conditions, Genes, and Chromosomes pages
- New features
  - 60 Test Your Knowledge Quizzes
  - Evaluating Internet Health Information Tutorial
- Maintenance
  - 8597 links to trusted health information

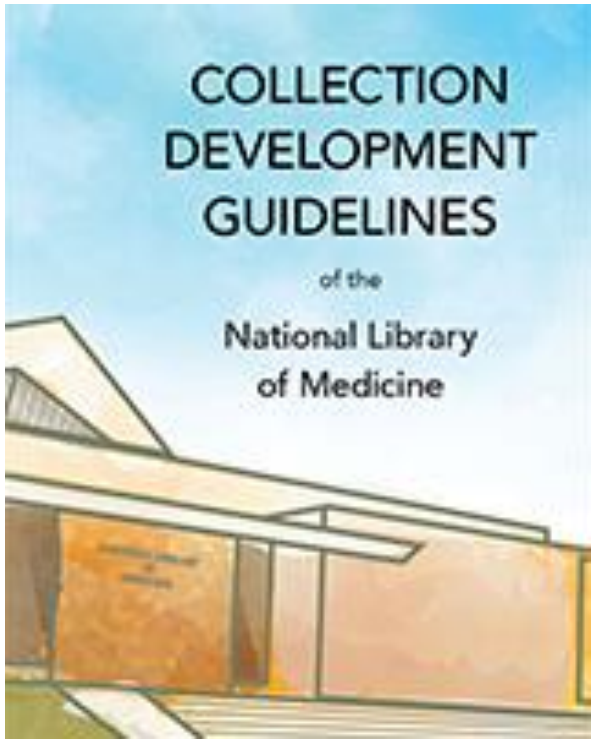


DOCLINE Update

-DOCLINE move to the cloud
-Library group managing their own groups
-Updated reports to provide options for PDF and Excel
-13-month access activity summaries reports

DOCLINE Release Notes: www.nlm.nih.gov/docline/support/releases.html

Collection Development Update



- All selection and acquisition work for the collection has been consolidated into one program area, regardless of age or format of the material.

- Updates to the Collection Development Guidelines
  - Datasets
  - Drafts
  - NLM Retention Policy

NLM Collection Development Guidelines: https://www.ncbi.nlm.nih.gov/books/NBK518693/

Government Initiatives

- Women's Health Initiative
- Open Science

Open Science

Administration Priorities The Record Bri

JANUARY 11, 2023

FACT SHEET: Biden-Harris Administration Announces New Actions to Advance Open and Equitable Research

OSTP › NEWS & UPDATES › PRESS RELEASES

OSTP launches Year of Open Science to advance national open science policies across the federal government in 2023

An official website of the United States government Here's how you know

Science.gov BETA

About Science.gov | Open Science & Public Access | Scientific Integrity

Search for authoritative federal science information

Advanced Search

Open Science Announcements from Federal Agencies

Open Science is the principle and practice of making research products and processes available to all, while respecting diverse cultures, maintaining security and privacy, and fostering collaborations, reproducibility, and equity.

Federal agencies are celebrating 2023 as a Year of Open Science, a multi-agency initiative across the federal government to spark change and inspire open science engagement through events and activities that will advance adoption of open, equitable, and secure science.

Help spotlight the value of open science by checking out this toolkit: choose and use images for social media, presentations, posters and virtual backgrounds—agency partners may even co-brand. #YearofOpenScience.

- Centers for Disease Control and Prevention
- Department of Agriculture
- Department of Commerce
- Department of Energy
- Department of State
- Department of Transportation
- Environmental Protection Agency
- National Aeronautics and Space Administration
- National Endowment for the Humanities
- National Institutes of Health
- National Institute of Standards and Technology
- National Oceanic and Atmospheric Administration
- National Science Foundation
- Smithsonian Institution
- U.S. Geological Survey
- U.S. General Services Administration
- White House Office of Science and Technology Policy

Open Science

OFFICIAL DEFINITION:

The principle and practice of making research products and processes available to all, while respecting diverse cultures, maintaining security and privacy, and fostering collaborations, reproducibility, and equity.

Open Science

Learn more at Musings from the Mezzanine

Lowering Barriers, Fostering Discovery: How NLM is Supporting A Year of Open Science

Posted on August 30, 2023 by Guest Author

Guest post by colleagues at NLM's Lister Hill National Center for Biomedical Communications (LHNCBC).

A Year of Open Science, A Lifetime Commitment for NLM

Posted on July 26, 2023 by Guest Author

Guest post by Lisa Federer, PhD, Acting Director of the Office of Strategic Initiatives, National Library of Medicine (NLM).

Women's Health

Key areas of support and advancement:

- Prioritize and Increase Investments in Women's Health Research
- Foster Innovation and Discovery in Women's Health
- Expand and Leverage Data Collection and Analysis Related to Women's Health
- Strengthen Coordination, Infrastructure, and Training to Support Women's Health Research
- Improve Women's Health Across the Lifespan

Women's Health Initiative

How will NLM be contributing?

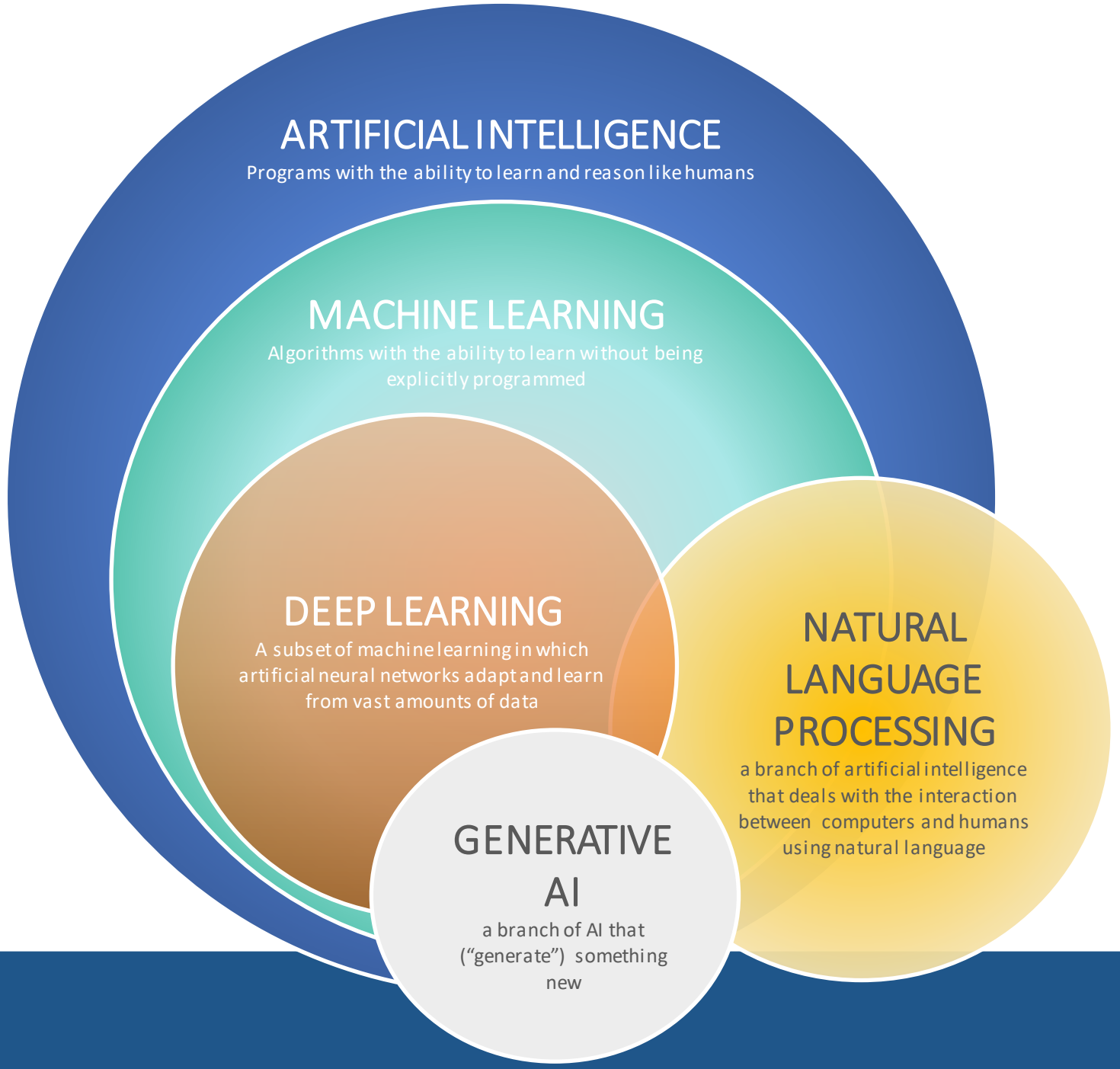
Delivering a federated information ecosystem for women's health information to be organized and accessible

AI @ NLM

- Background
- GenAI in the Scientific Landscape
- Community of Practice
- Pilot Update

Artificial Intelligence Defined

A key building block of an AI system is the ability to learn from large datasets.



How We Got Here

1990s:
The public surfs web browsers.

PubMed

PMC

MTI

2000s:
Smartphones connect to the internet.

BD2K

2010s:
Big data & advances in hardware enable breakthroughs in AI research.

Early 2020s:
OpenAI, Google, Microsoft, Meta and Latimer make a splash with Gen AI products.

NLM GenAI Pilot

GenAI Pilot Goals

Experiment and develop best practices for LLMs in Azure's "playground" (safe zone)

Create a proof of concept that applies to NLM work

Measure results to ensure utility and safety (NIST)

Develop workforce skills in Generative AI

Use Cases (10)

Responsive Customer Service	Classification and Web Accessibility
	Customer Response
	Product Knowledge Insights
Operational Process Efficiency	IT Programming Tasks
	Metadata Retrieval and Transformation
	UMLS Edit Support
Summarization and Analysis	Data Viz and Segmentation
	EP Grant Portfolio Analysis
	Network Analysis
Clinical Support Assistance	Research and Development: TrialGPT

GenAI Pilot Impact

Cohort Logistics

10 Use Cases

15 Pilot Participants

Participant/ Technical Support

~300 One-on-one Consults

~30 Office Hours

Communications

35 Demos

6 NLM/NIH Leadership Briefings, NLM Town Hall, Board of Regens, NLM Insider

3 External Publications

NIH GenAI Community of Practice

Vision and Goals

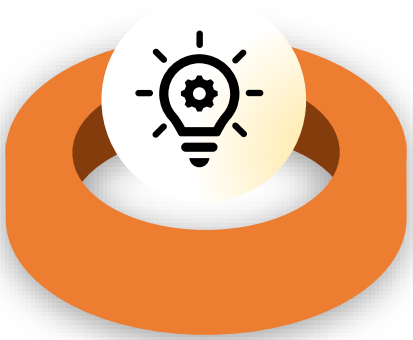
- Harness the potential of GenAI across NIH to enable biomedical research discoveries and accelerate NIH business operations
- Serve as the nexus for GenAI coordination, innovation, and deployment across the NIH community
- Encourage, test, support, and scale GenAI adoption at NIH

Lessons Learned from GenAI Pilot

Importance of Technical Support

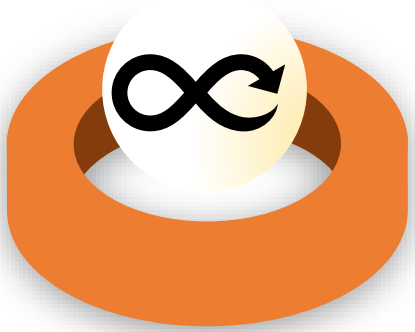
Field is embryonic and dynamic so robust, 1:1 technical support and training resources mitigates challenges in technology adoption and implementation.

Value of Collaboration and Networking



Cohort collaboration, knowledge sharing, and networking facilitated problem-solving and idea generation, and a more enriching learning experience.

Standardized Project Mmgt. Resources



Rapid, iterative innovation needs SOP creation and project management tools to help address issues related to access, resource allocation, and technical resolution.

Human-in-The-Loop Design

To automate pieces of workflows, we need to design and plan for human monitoring of certain checkpoints in accuracy and ethics.

Why Support this Work?

Drives Mission

Future-forward visioning and responsible use of emergent technologies is essential for NLM>NIH to achieve its mission and drive national competitiveness.

Trusted Reputation

NLM has a reputation for providing *trusted* and *well-structured* biomedical standards, computational research, and leading science for the public globally.

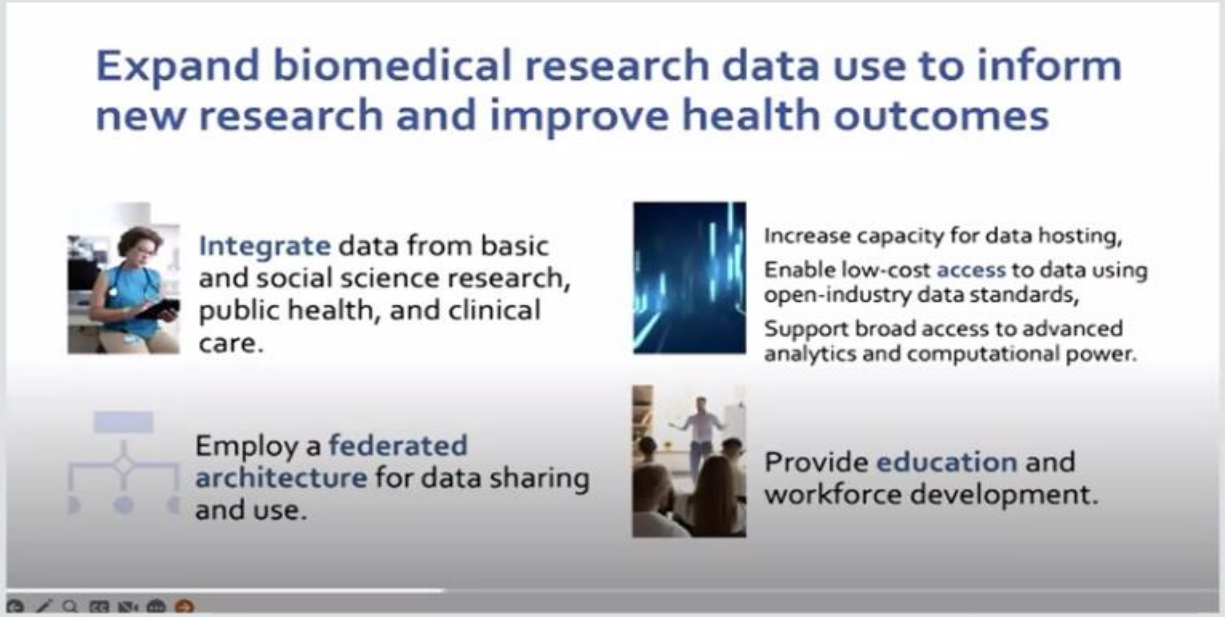
Curation Expertise

NLM has a rich, large, highly curated repository of information and domain data ideal for secure GenAI.

Workforce Capacity

Humans-in-the-loop verification is essential to sustain internal workforce capability and trustworthy products and services.

NIH's Vision for NLM



"In order to make the best use of this influx of data, I hope to make **NLM a revitalized hub for expanded biomedical data, research data, use**, not just data sharing, not just data storage, but focus on data use, that is able to inform new research and improve health outcomes."

"...**get the right data in the hand of people asking important questions, integrate data** from basic and social science research public health and clinical care..."

Long-term Vision: Connecting Everyone with Customized Health Information

User asking a health or medicine-related question and/or entering a search query to a user interface.

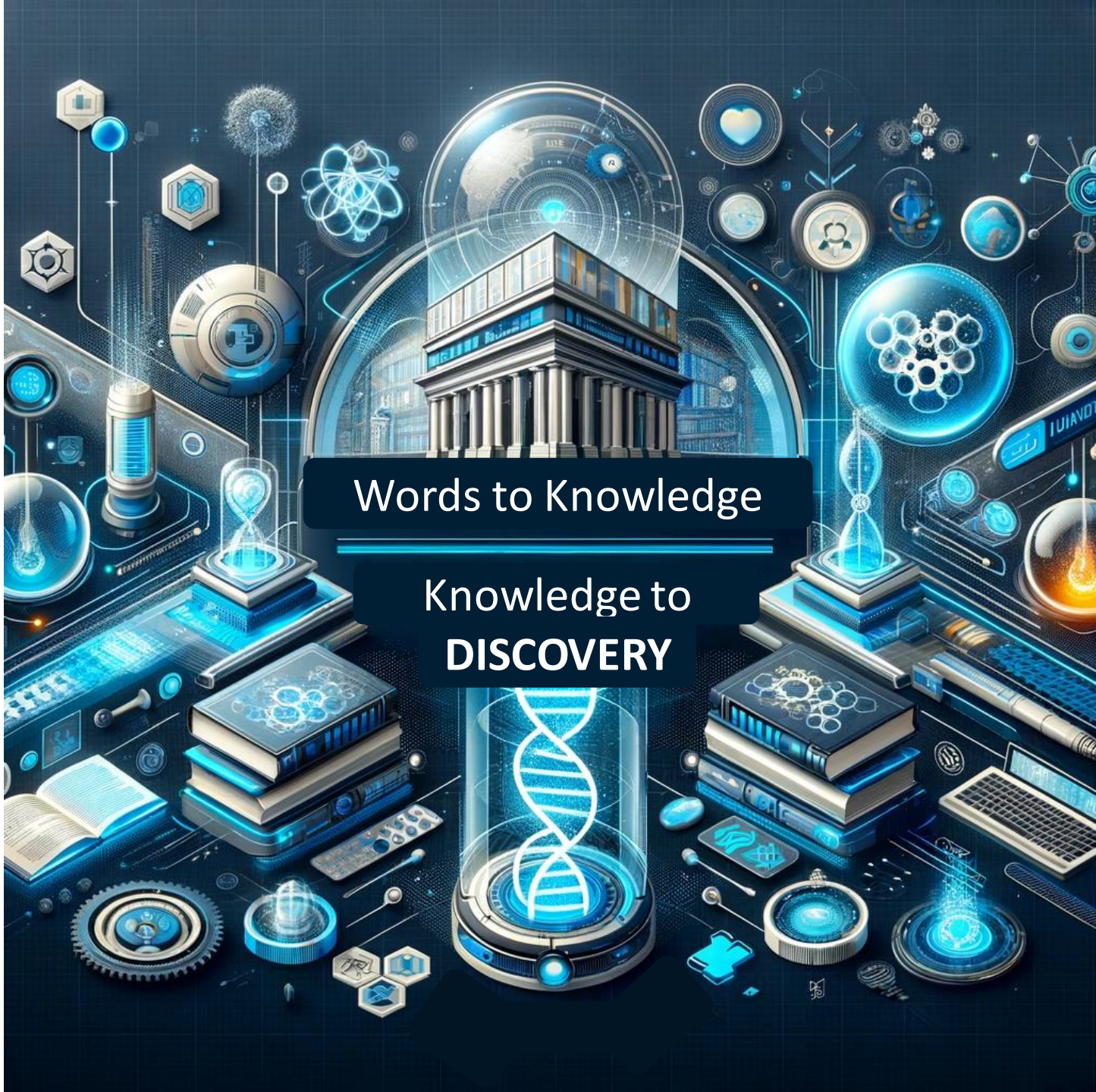
Synthesized knowledge coming back to the user.

NLM Strategic Plan

Accelerate discovery and advance health through data-driven research

Reach more people in more ways through enhanced dissemination and engagement

Build a workforce for data-driven research and health



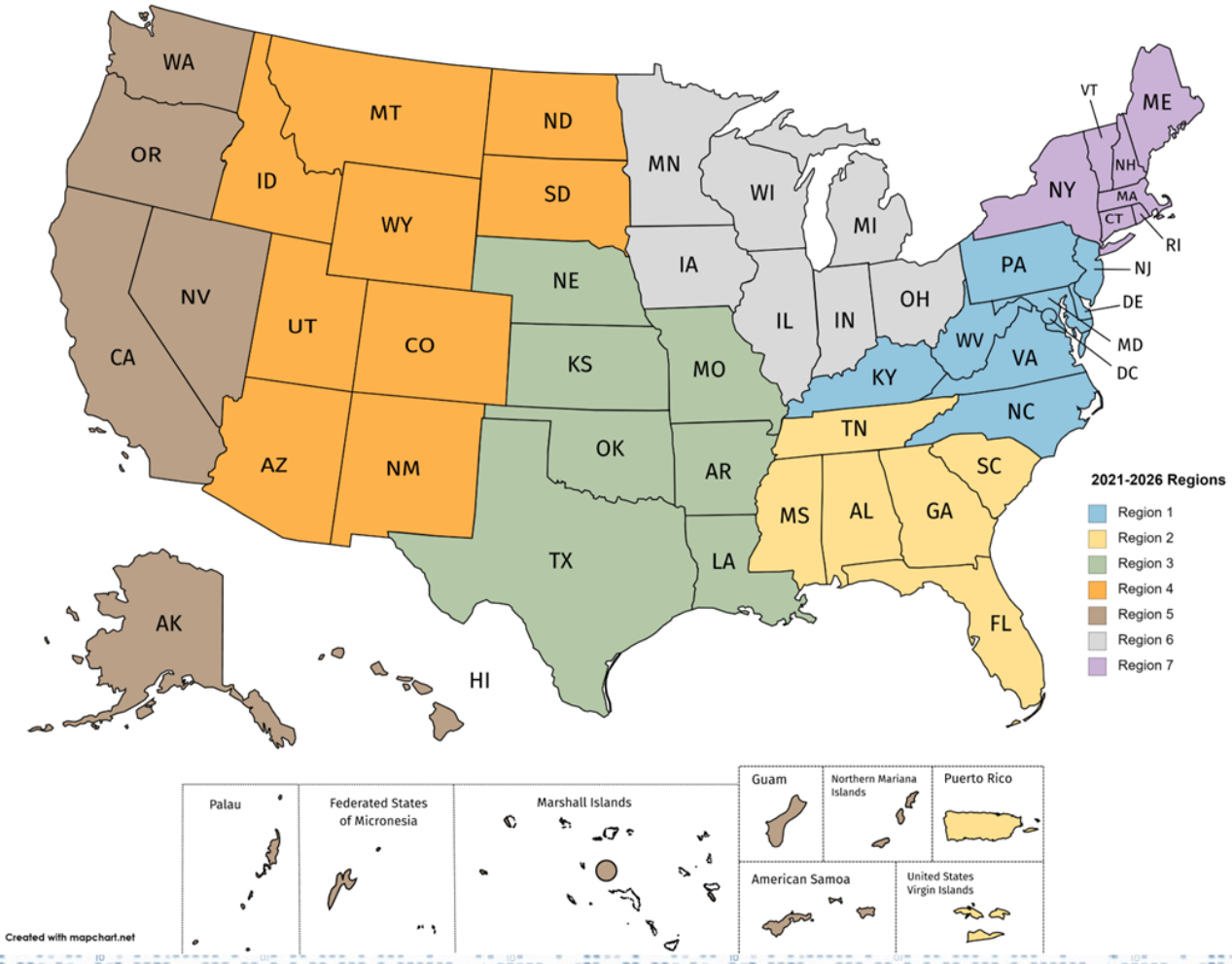
NNLM Network of the National Library of Medicine

Martha Meacham

Project Director, Network of the National Library of Medicine

Martha.Meacham@nih.gov

Network of the National Library of Medicine (NNLM)



Regional Medical Libraries

- **Region 1 - University of Maryland, Baltimore**
- **Region 2 - Medical University of South Carolina**
- **Region 3 - University of North Texas Health Science Center**
- **Region 4 - University of Utah**
- **Region 5 - University of Washington**
- **Region 6 - University of Iowa**
- **Region 7 - University of Massachusetts Medical School**

Coordinating Offices / Centers

- **NNLM Web Services Office (NWSO)**
- **NNLM Training Office (NTO)**
- **NNLM Public Health Coordination Office (NPHCO)**
- **NNLM Center for Data Services (NCDS)**
- **NNLM Evaluation Center (NEC) - Northwestern**
- **NNLM *All of Us* Program Center (NAPC) – Uiowa & UPitt**

Training

Year 3 (May 2023 – April 2024)

- NNLM.gov/training
- 30,000+ registrations
- 230+ classes
- Total MLA CE Credits Offered: 564
- NNLM YouTube - https://www.youtube.com/c/NnlmGov

I have found the trainings I've attended over the past two years to be a remarkable resource in updating my skills and introducing me to current issues in medical librarianship. With each training and patron interaction, I feel better equipped to connect patients with reliable health information. Thank you for offering this caliber of training. - From NEC Follow-up Training Survey

Data & AI

- MLA Data Science Specialization
- Data Pathways (https://www.nnlm.gov/guides/data-pathways)
- Fundamentals of Data Science Course
- AI and Libraries
- NCDS Data Internship

NNLM DATA PATHWAYS
routes to data librarianship

NNLM FUNDAMENTALS OF HEALTH DATA SCIENCE

"The speakers offered a fascinating overview/update and analysis of all things AI for those in healthcare, education and libraries. It was the best one I've seen so far on the topic of AI and libraries." - The Future Will See You Now: AI for Healthcare, A Library's Perspective, hosted by Brandon Kennedy, R3

Student Engagement

- Internships
- Professional Development
- Alternative Spring Break
- Work with LIS/iSchools
- LIS Students receiving CHIS

"This internship kept me focused on health librarianship during my last semester of school. My school didn't have a health sciences emphasis, so this internship gave me much needed experience. I learned a lot about the social determinants of health, health data, and where to find health data. Then compiled the data for a single county and presented it in the Community Guide to Advance Health Information Equity." *Annisija Hunter, MLIS student at the University of Missouri*

...And More

- Funding
- Rural and Tribal
- Skills for Health Science Librarians
- Telehealth -> Digital Health
- Traveling Exhibitions
- Evaluation

NNLM Discovery Podcast
NNLM.gov/Podcast

"It was fantastic to see a project of this kind where an indigenous researcher went into the community and performed research with a cultural understanding of the population." - Developing, implementing, and evaluating a mixed-methods community-based participatory research sleep intervention, hosted by Carolyn Martin, R5

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Thank you, MLA!