



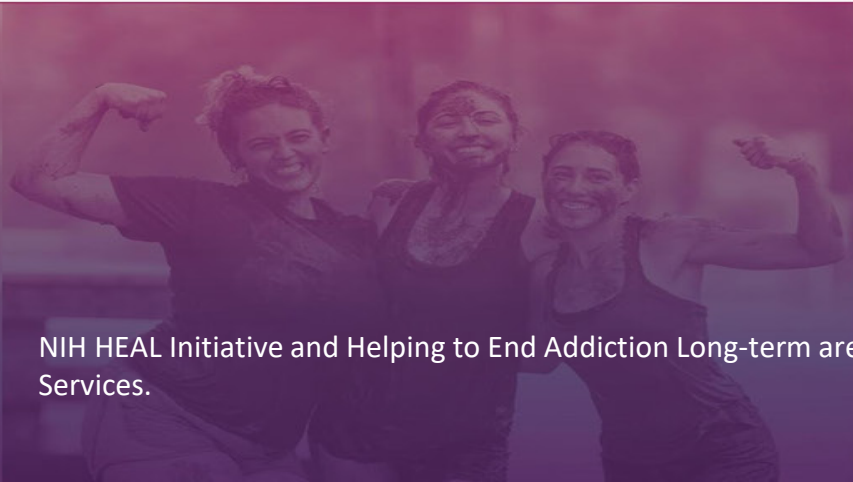
@NIHendaddiction

**NIH
HEAL
INITIATIVE**

HEAL Data Strategy: A Distributed Approach to Maximize Flexibility

Jess Mazerik

**HEAL Data Ecosystem Director
Office of the Director, NIH**



NIH National Institutes of Health
HEAL Initiative

NIH HEAL Initiative and Helping to End Addiction Long-term are service marks of the U.S. Department of Health and Human Services.

NIH HEAL Initiative: Scientific Solutions for the National Pain, Opioid and Overdose Crisis

- Over \$2.5 billion in research
- 42 research programs
- More than 1000 awards
- Projects underway in all 50 States

NIH HEAL INITIATIVE RESEARCH OVERVIEW

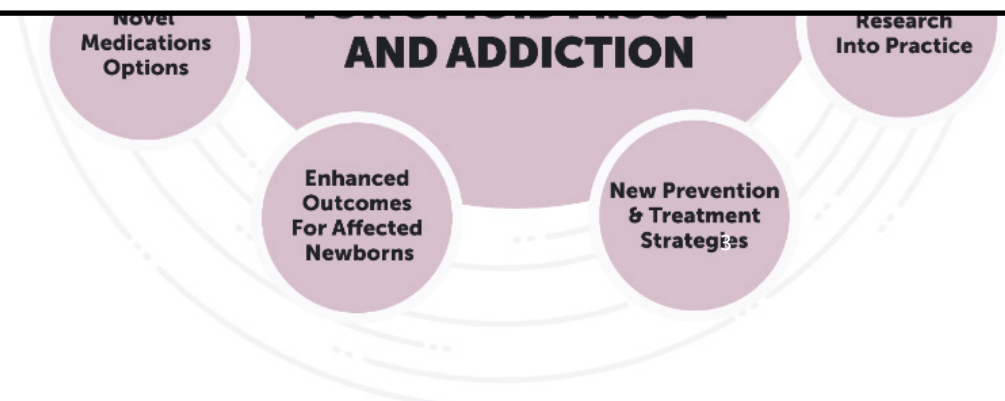


NIH HEAL Initiative: Scientific Solutions for the National Pain, Opioid and Overdose Crisis

NIH HEAL INITIATIVE RESEARCH OVERVIEW

HEAL Policy + Principles: Open science and data sharing are critical for moving forward and translating discoveries into solutions

- ***Open access publications***
- ***Data sharing and discoverability***
- ***Translating data to knowledge and action***



HEAL Public Access & Data Sharing Policy

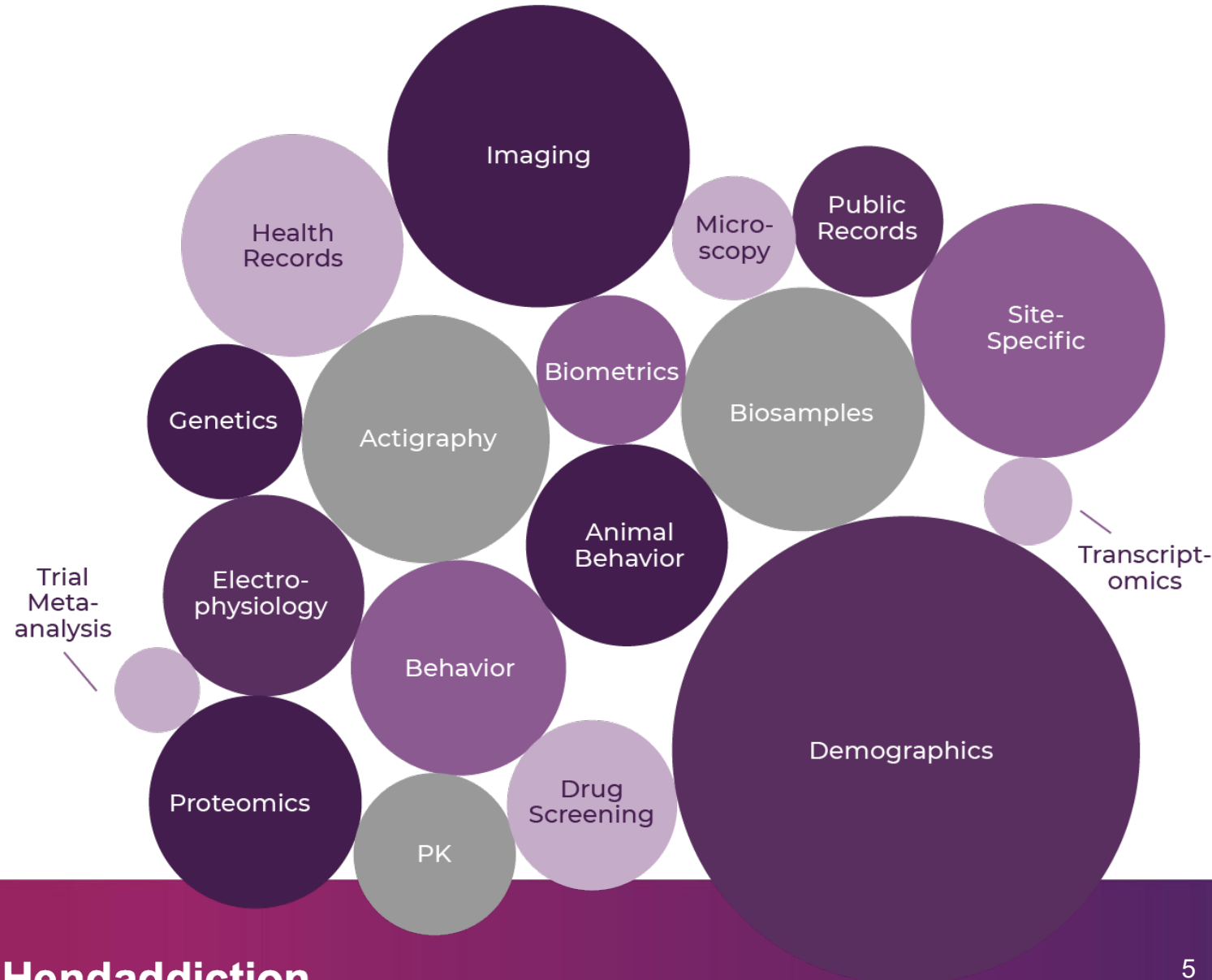
MAIN ELEMENTS

1. Submitting & following a data management & sharing plan
2. Open access to publications
3. Sharing of underlying primary data

<https://heal.nih.gov/data/public-access-data>

Challenge: how do we address vast variation?

- Almost all institutes & centers involved
- 1000+ HEAL awards
- All study type imaginable
- Diverse data types
- Various levels of expertise and data support



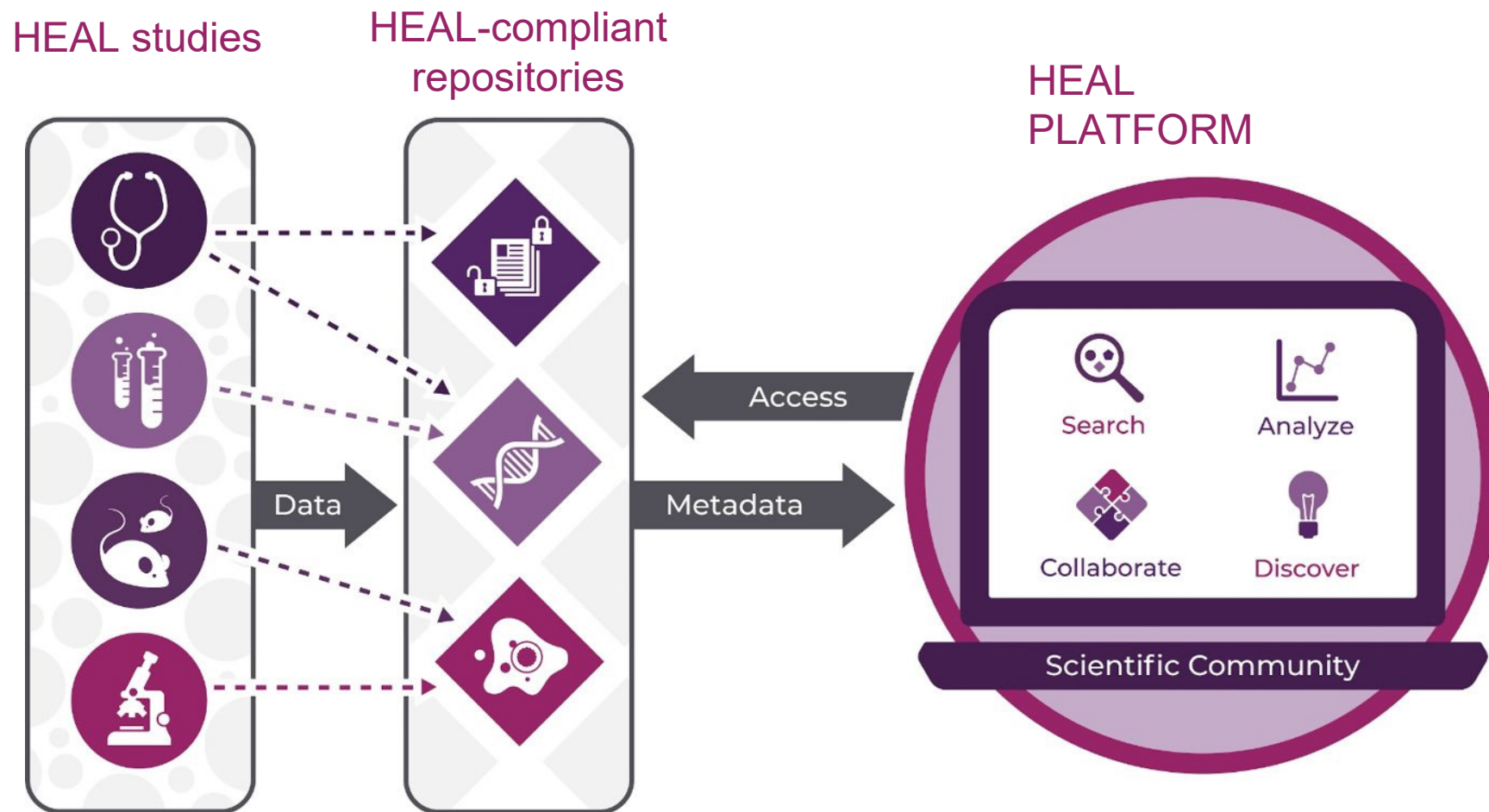
Challenge: how do we address vast variation?

- Almost all institutes & CE
- 1C
- AI
- Di
- Various levels of expertise and data support

VERY FLEXIBLY!



A Distributed Approach to Meet Investigators “Where they are”



HEAL Data Ecosystem Goals

Make HEAL data accessible

- HEAL-generated data indexed and searchable, with clear routes to access
- Data management & sharing support
- User-friendly search & interface

Provide the 'sandbox'

- Secure cloud computing
- Analytical tools
- Diverse, representative datasets
- Key overdose & pain datasets
- Data harmonization and reuse to address critical research questions

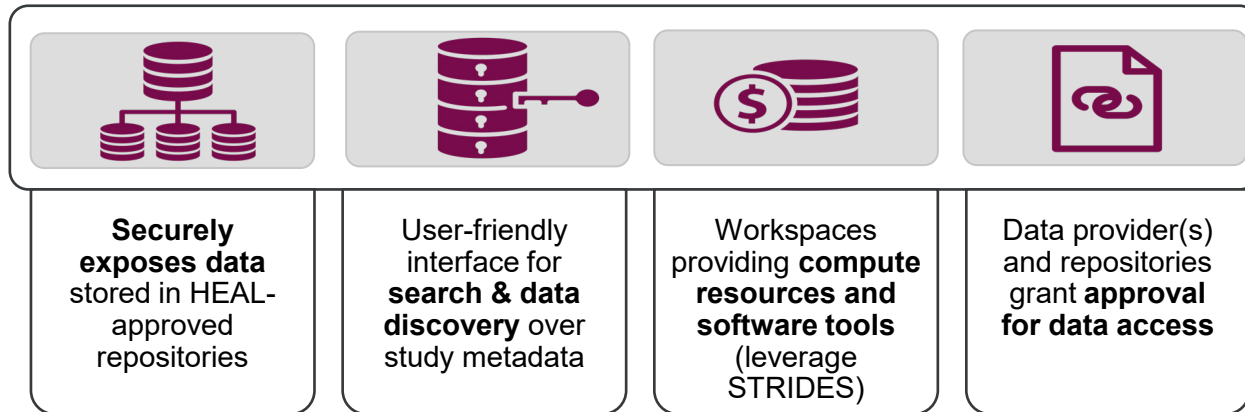
Build the community

- HEAL PI engagement and consensus-building, foster cross-awareness of research projects and drive collaborations
- Broad researcher, stakeholder & user studies
- Open communication to diverse audiences and communities
- Feedback loops for input; co-learning through engagement

Supporting HEAL Investigators to Integrate with the Ecosystem

Data Platform

Build web-based infrastructure for search, discovery, compute and analyses



Data Stewards

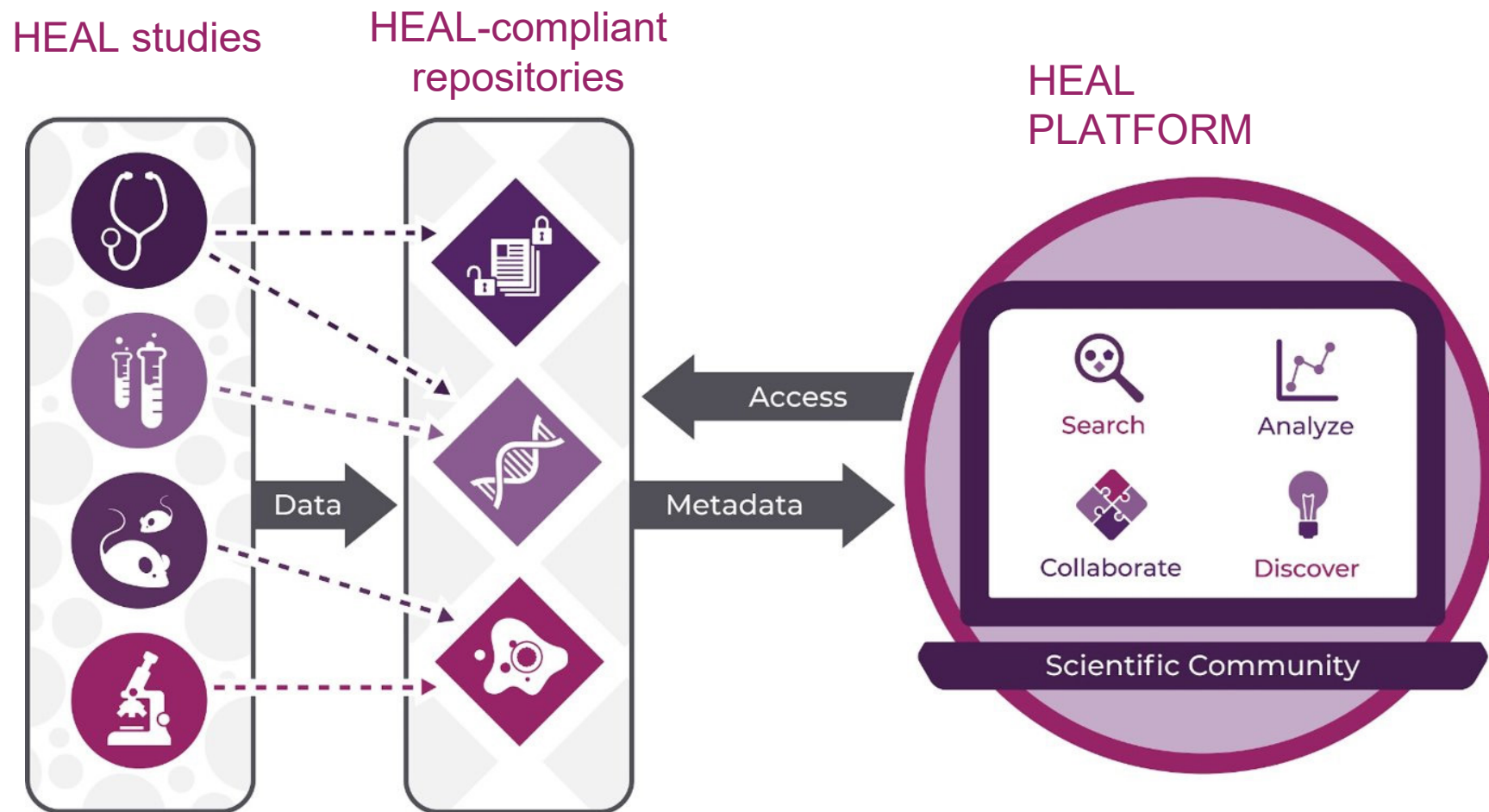
Consulting on storage and management, engagement, harmonization via use cases



Building community and consensus: HEAL Data Ecosystem Collective Board

- **Meredith Adams**, Wake Forest School of Medicine
- **Emine Bayman**, University of Iowa
- **Marisa Briones**, BDH Pharma
- **Abhik Das**, RTI International
- **Mike Dean**, University of Utah School of Medicine
- **Georgene Hergenroeder**, University of Texas Health Science Center at Houston
- **Steve Johnson**, New York University Grossman School of Medicine
- **Charlie Knott**, RTI International
- **Jessica Magidson**, University of Maryland
- **Rosemarie Martin**, Brown University
- **Micah McCumber**, UNC Gillings School of Global Public Health
- **Pilar Ossorio**, University of Wisconsin–Madison
- **Ty Ridenour**, RTI International
- **Abeed Sarker**, Emory University School of Medicine
- **Chelsea Shover**, UCLA David Geffen School of Medicine
- **Wes Thompson**, Laureate Institute for Brain Research
- **Anca Tilea**, University of Michigan

A Distributed Approach to Meet Investigators “Where they are”



A Distributed Approach to Meet Investigators “Where they are”

HEAL

||| COLUMNS ¹ FILTERS ≡ DENSITY ↓ EXPORT

Repository	Descriptive ... ▼	Organism	IC/Program Required?
Vivli	Clinical Trial, Generalist	Human	No
Figshare	Generalist	Unrestricted	No
Dryad	Generalist	Unrestricted	No
Dataverse	Generalist	Unrestricted	No
Mendeley Data	Generalist	Unrestricted	No
OpenScience Framework	Generalist	Unrestricted	No
Zenodo	Generalist	Unrestricted	No



Flexible metadata model

- HEAL Study Registration in Platform
 - Collects info about HEAL study in Platform, connects different databases to pull metadata and decrease work for investigator
 - APPL-ID, selected repository, CEDAR user ID, Clinical Trial ID if applicable
- Metadata
 - Data that provide additional information intended to make scientific data interpretable and reusable¹
 - Enables collaboration and cross-study analysis - the richer the metadata, the more value added to a study or dataset
 - Collected with CEDAR as subset of registration information
 - Accessible to repositories – supplements value of generalist repositories



Generalist Repositories in the HEAL Strategy

Flexibility meets our model!

- metadata - investigators can leverage Platform metadata at repos to increase data searchability and reusability
- open - a “home” for investigators without IC-specified repositories
- data types - studies with multiple data types can leverage one repo

**Follow the
NIH HEAL Initiative[®]
on Twitter**



@NIHendaddiction

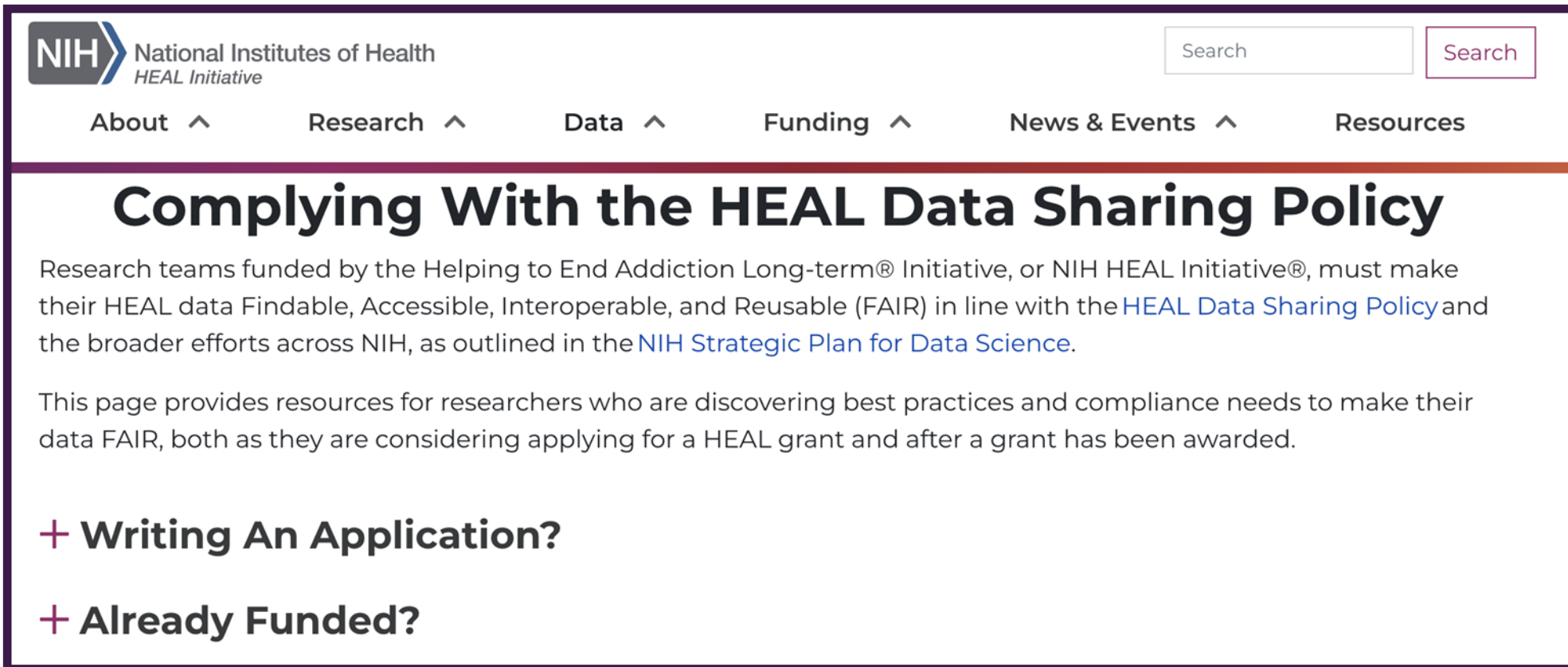
NIH Data Sharing Policy: Effective Jan 2023

The screenshot shows the NIH Scientific Data Sharing website. The header includes the NIH logo and the text 'SCIENTIFIC DATA SHARING'. A search bar is located in the top right corner. Below the header, there are navigation links: 'DATA MANAGEMENT AND SHARING POLICY' (highlighted), 'GENOMIC DATA SHARING POLICY', 'OTHER SHARING POLICIES', 'ACCESSING DATA', and 'ABOUT'. The main content area features a breadcrumb trail: 'Home > Data Management and Sharing Policy > Data Management & Sharing Policy Overview'. The title is 'Data Management & Sharing Policy Overview'. Below the title, there is a sub-header: 'Learn what is expected of investigators and institutions under the 2003 NIH Data Sharing Policy and the 2023 NIH Data Management & Sharing Policy.' At the bottom, there are two buttons: 'Applications for Receipt Dates BEFORE Jan 25 2023' and 'Applications for Receipt Dates ON/AFTER Jan 25 2023'.

HEAL Data Ecosystem requirements & resources align with new NIH policy everyone will have to meet in Jan 2023

<https://sharing.nih.gov/>

Applicants: Building a HEAL-compliant Data Management & Sharing Plan



The screenshot shows the NIH HEAL Initiative website. At the top left is the NIH logo and the text 'National Institutes of Health HEAL Initiative'. To the right is a search bar with the text 'Search' and a 'Search' button. Below the logo is a navigation menu with links for 'About', 'Research', 'Data', 'Funding', 'News & Events', and 'Resources'. The main content area has a large heading 'Complying With the HEAL Data Sharing Policy'. Below the heading is a paragraph of text: 'Research teams funded by the Helping to End Addiction Long-term® Initiative, or NIH HEAL Initiative®, must make their HEAL data Findable, Accessible, Interoperable, and Reusable (FAIR) in line with the [HEAL Data Sharing Policy](#) and the broader efforts across NIH, as outlined in the [NIH Strategic Plan for Data Science](#).' Below this paragraph is another paragraph: 'This page provides resources for researchers who are discovering best practices and compliance needs to make their data FAIR, both as they are considering applying for a HEAL grant and after a grant has been awarded.' At the bottom of the page are two expandable sections: '+ Writing An Application?' and '+ Already Funded?'

NIH National Institutes of Health
HEAL Initiative

Search Search

About ^ Research ^ Data ^ Funding ^ News & Events ^ Resources

Complying With the HEAL Data Sharing Policy

Research teams funded by the Helping to End Addiction Long-term® Initiative, or NIH HEAL Initiative®, must make their HEAL data Findable, Accessible, Interoperable, and Reusable (FAIR) in line with the [HEAL Data Sharing Policy](#) and the broader efforts across NIH, as outlined in the [NIH Strategic Plan for Data Science](#).

This page provides resources for researchers who are discovering best practices and compliance needs to make their data FAIR, both as they are considering applying for a HEAL grant and after a grant has been awarded.

+ Writing An Application?

+ Already Funded?

Checklist for HEAL-compliant data

Step by Step Guide for HEAL-Compliant Data

This roadmap guides HEAL-funded investigators in complying with the [HEAL Public Access and Data Sharing Policy](#). Regardless of when you received your HEAL award, please start at the beginning, as the steps are generally in chronological order.



Award Received

Congratulations on your HEAL award! This roadmap will guide you through the steps to complying with the [HEAL Public Access and Data Sharing Policy](#).

Related Links

- [Guidance for complying with the HEAL Data Sharing Policy](#)
- [NIH Policy for Data Management and Sharing, going into effect January 2023](#)

CONTINUE



Provide your Data Management and Sharing Plan to the HEAL Stewards



Register your Study on ClinicalTrials.gov



Register your Study with the HEAL Data Platform



Complete your Study-level Metadata Form



Select a Repository



Use HEAL Common Data Elements to Collect Your Data



Submit Data and Metadata to a Repository



Report your Research Publication

HEAL Data Ecosystem Resources

NIH HEAL Platform
<https://healdata.org/landing>

Checklist for a HEAL-compliant
data management & sharing
plan:
<https://heal.nih.gov/data/complying-heal-data-sharing-policy>

Checklist for HEAL-compliant
data:
<https://www.healdatafair.org/resources/road-map>

Check out the HEAL Stewards
website!
www.healdatafair.org/

NIH HEAL Initiative
Common Data Elements (CDEs)
<https://heal.nih.gov/data/common-data-elements>

Fresh FAIR webinar series:
<https://www.healdatafair.org/webinar>

Join the HEAL Ecosystem
Slack:
<https://bit.ly/JoinHEALSlack>