


NIH
HEAL
INITIATIVE

HEAL Data Strategy: A Distributed Approach to Maximize Flexibility

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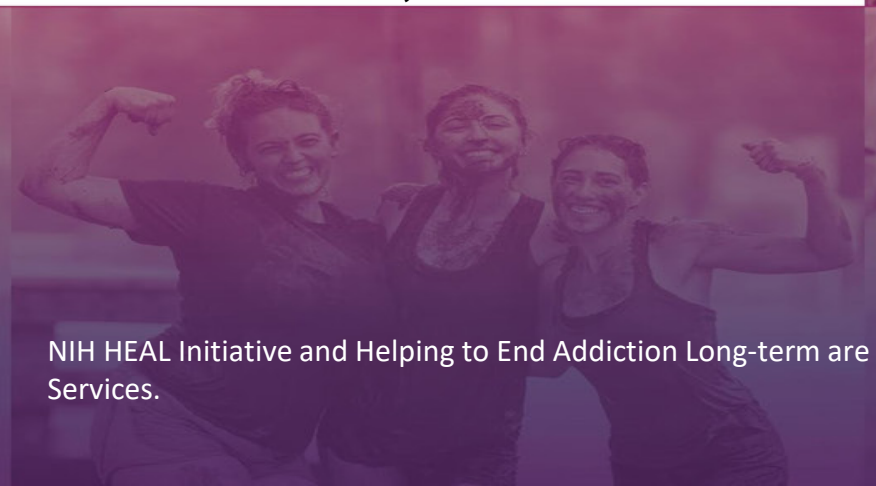



National Institutes of Health
HEAL Initiative

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

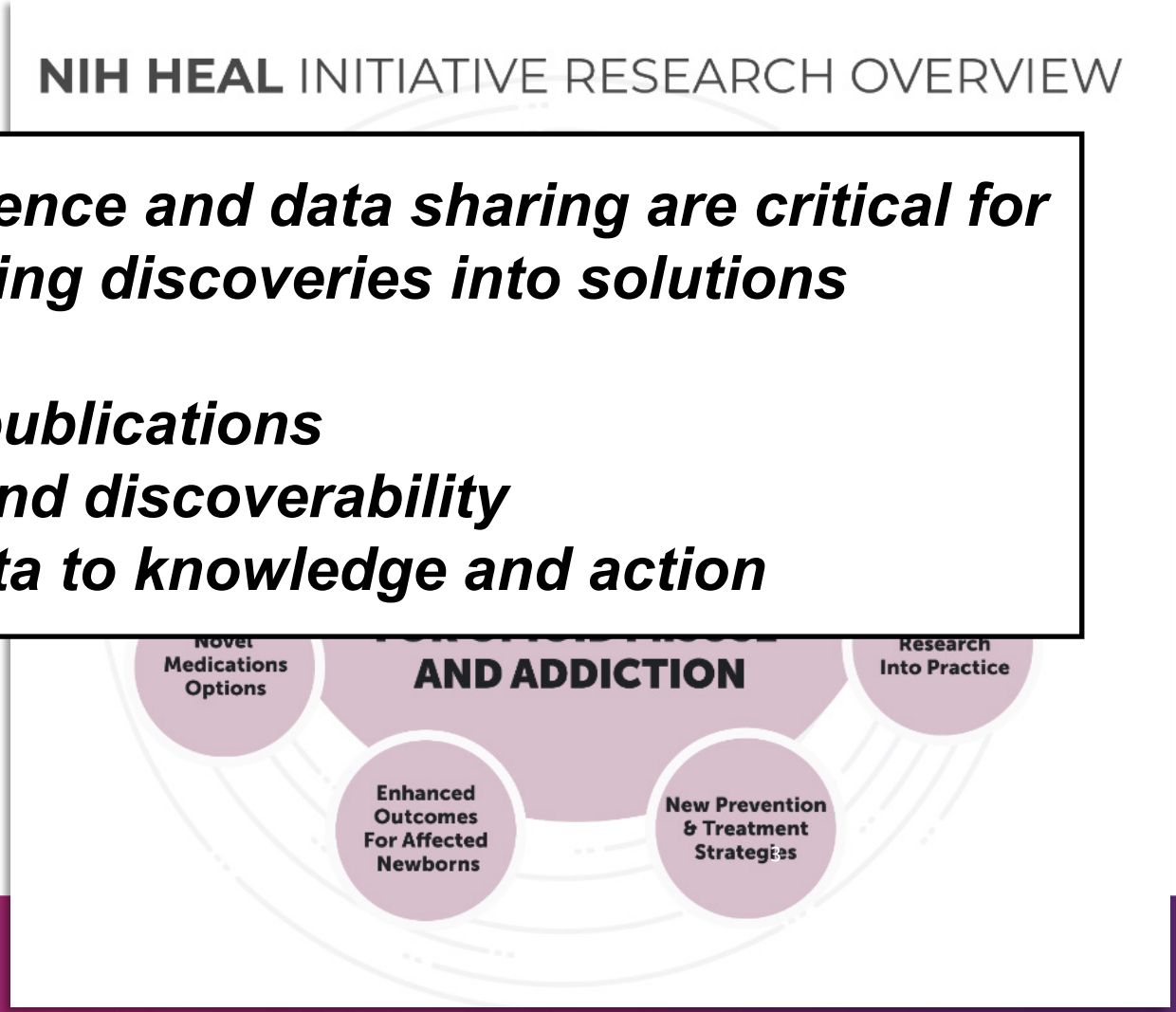
- Over $2.5 billion in research
- 42 research programs
- More than 1000 awards
- Projects underway in all 50 States

NIH HEAL INITIATIVE

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

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

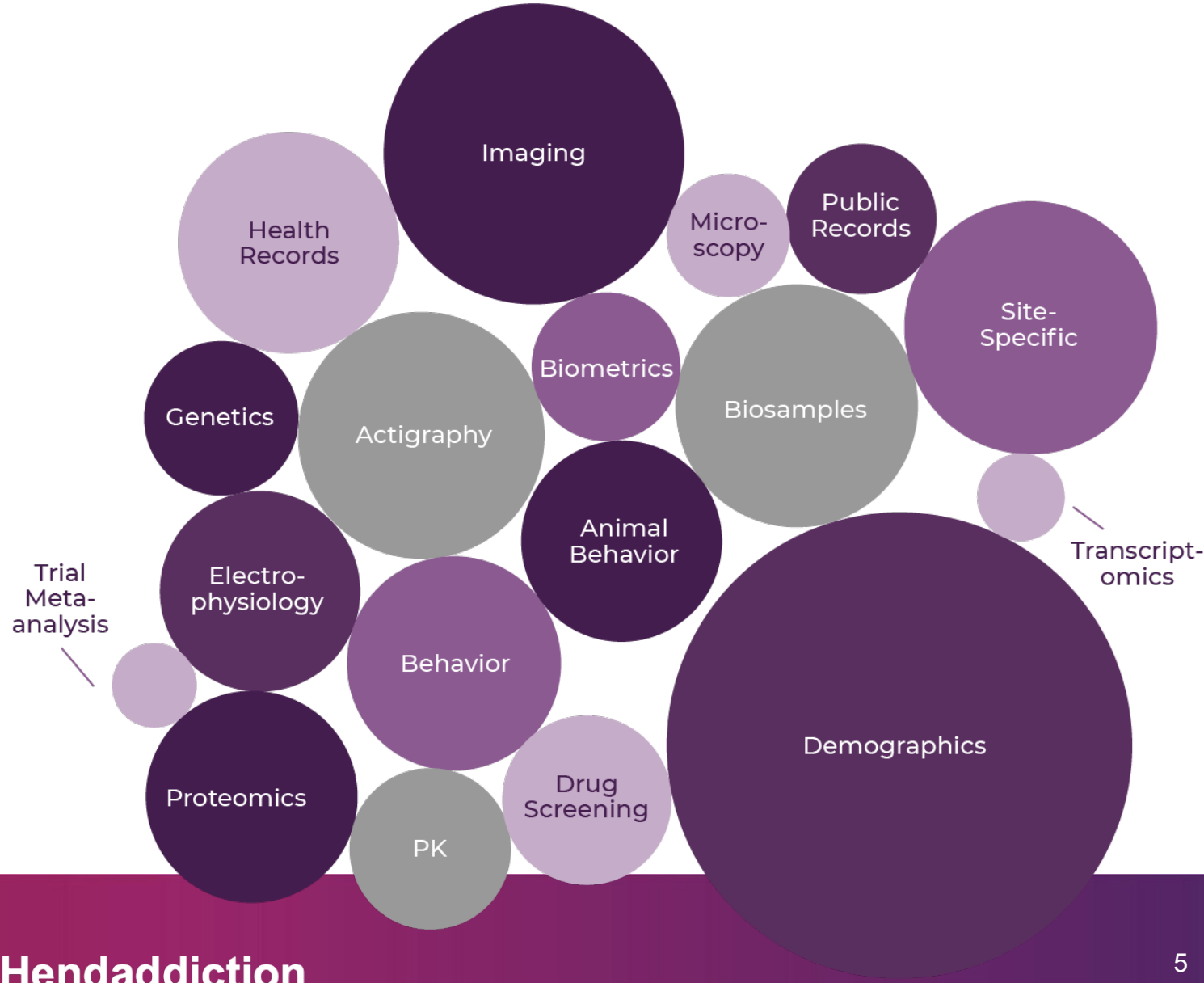
MAIN ELEMENTS

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?

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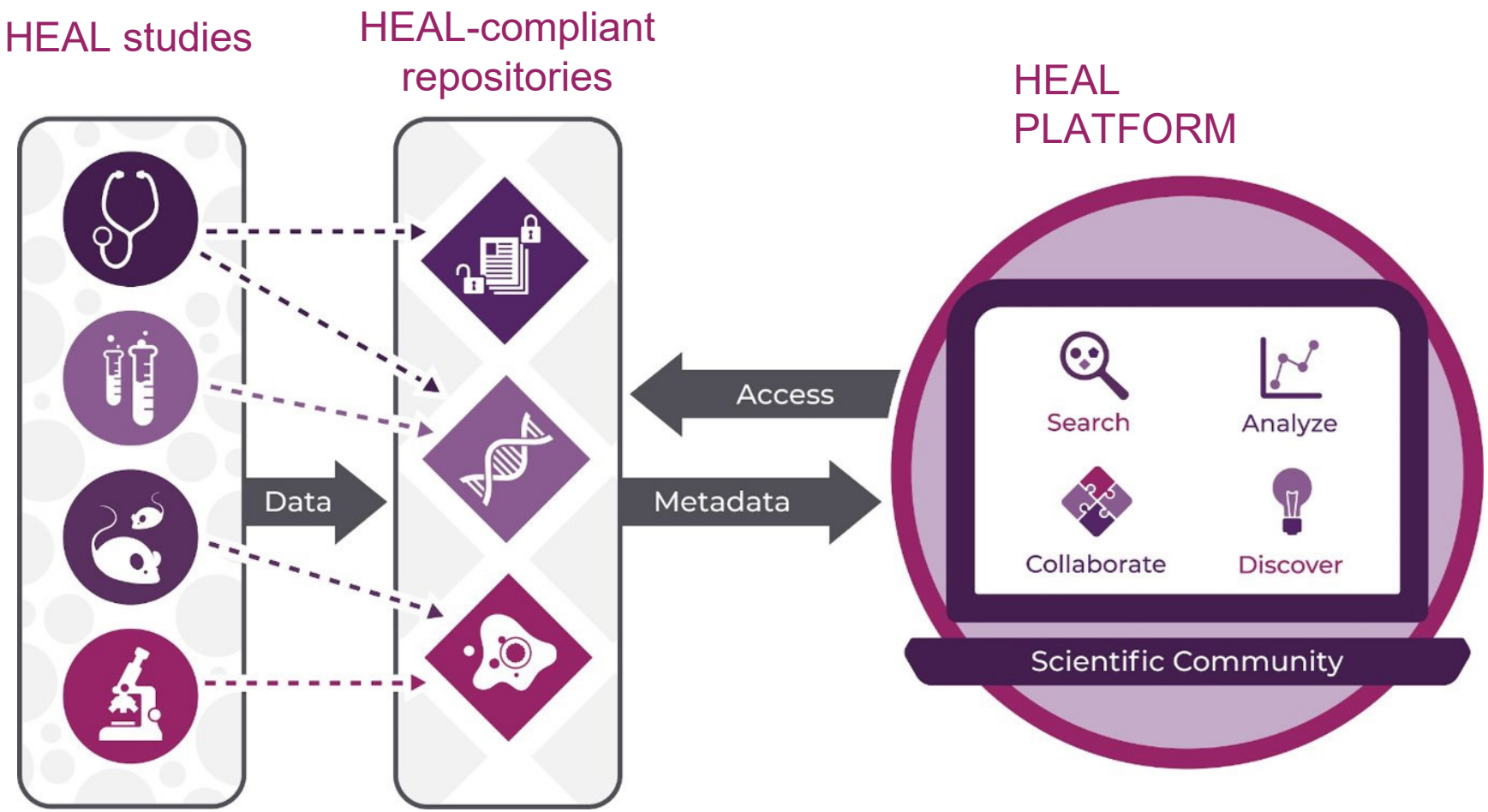
VERY FLEXIBLY!

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

Securely exposes data stored in HEAL-approved repositories	User-friendly interface for **search & data discovery** over study metadata	Workspaces providing **compute resources and software tools** (leverage STRIDES)	Data provider(s) and repositories grant **approval for data access**

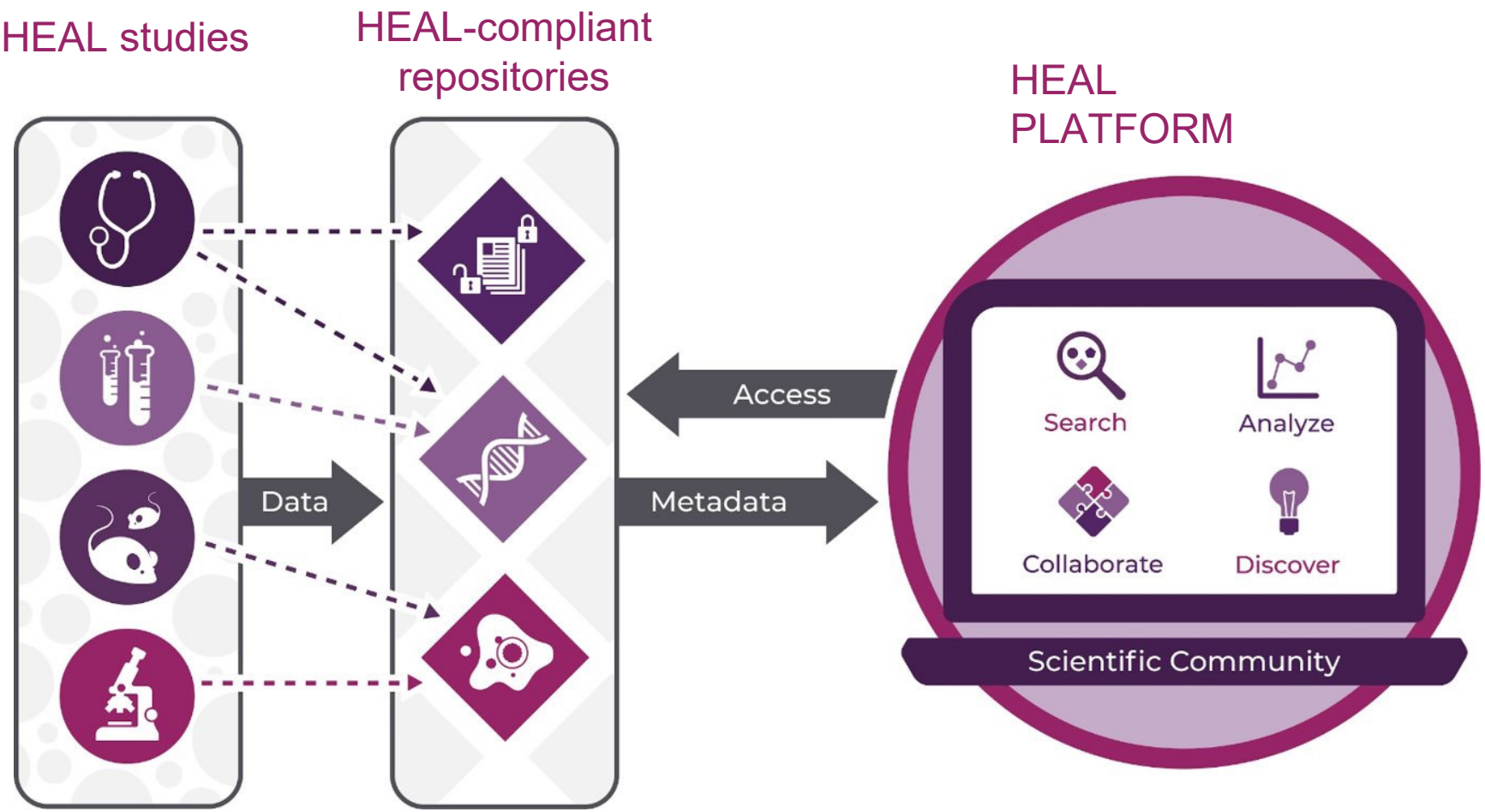
Data Stewards

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”



https://www.healdatafair.org/resources/guidance/selection

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

https://www.healdatafair.org/resources/guidance/selection

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 reusable[1]
  - 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 reusabilty
- open - a “home” for investigators without IC-specified repositories
- data types - studies with multiple data types can leverage one repo

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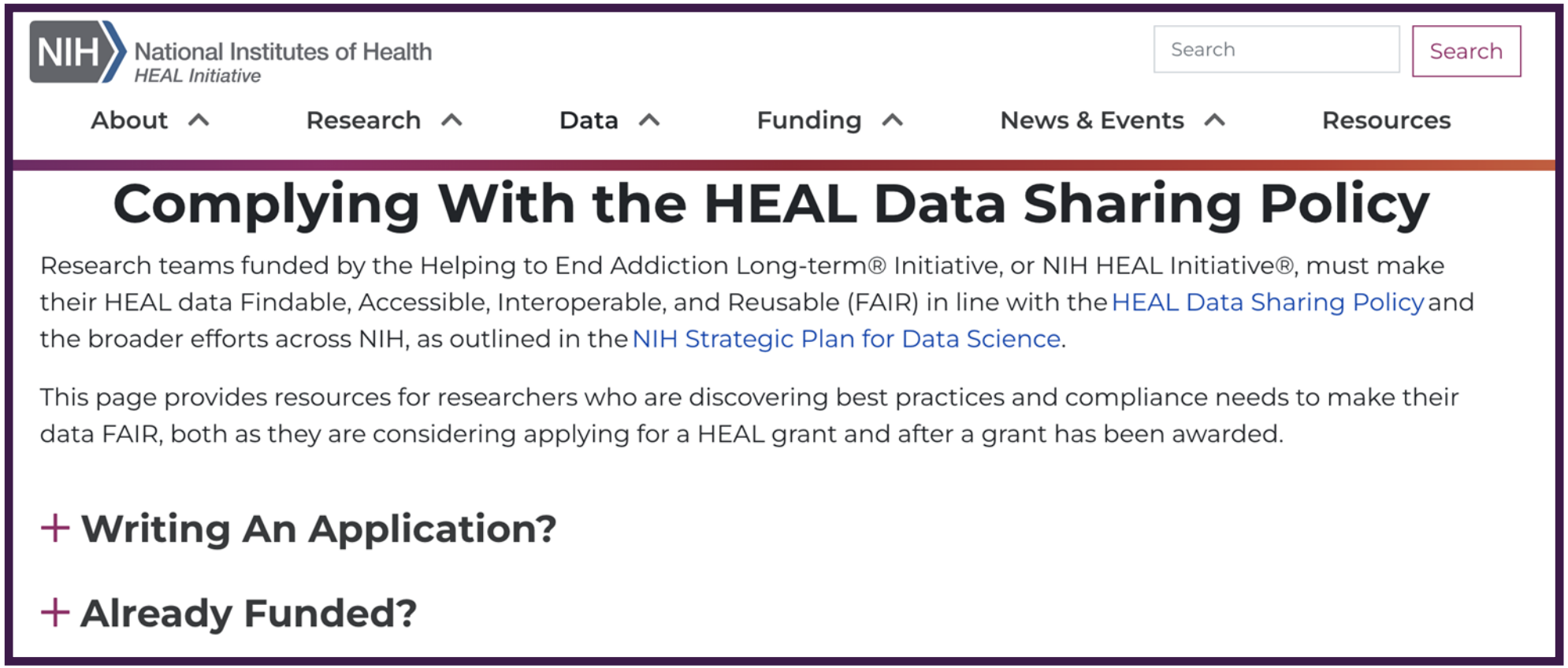
@NIHendaddiction

NIH Data Sharing Policy: Effective Jan 2023

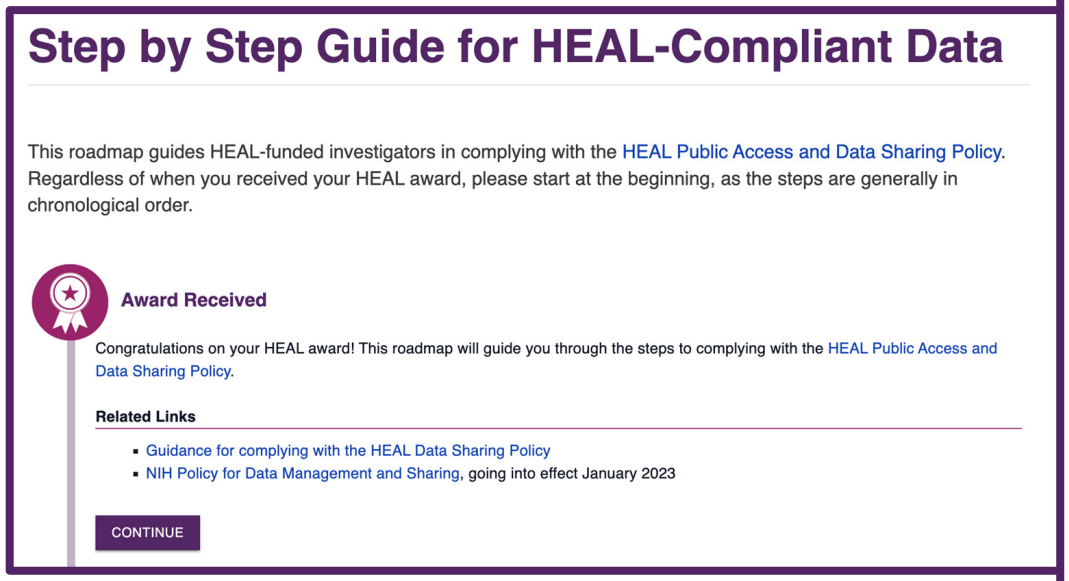
HEAL Data Ecosystem requirements & resources align with new NIH policy everyone will have to meet in Jan 2023

https://sharing.nih.gov/

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



Checklist for HEAL-compliant data



- 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

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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