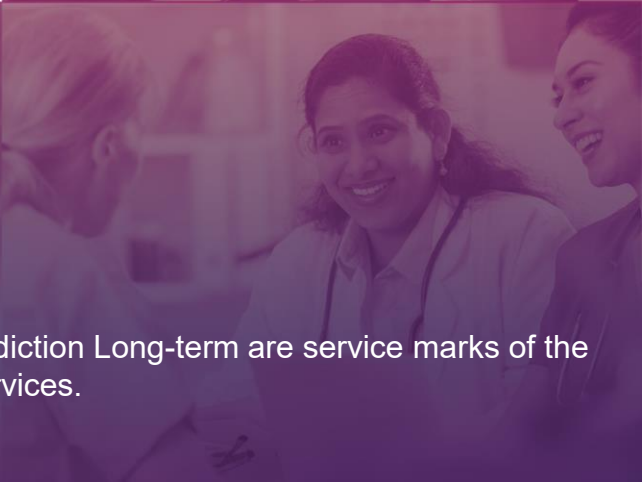
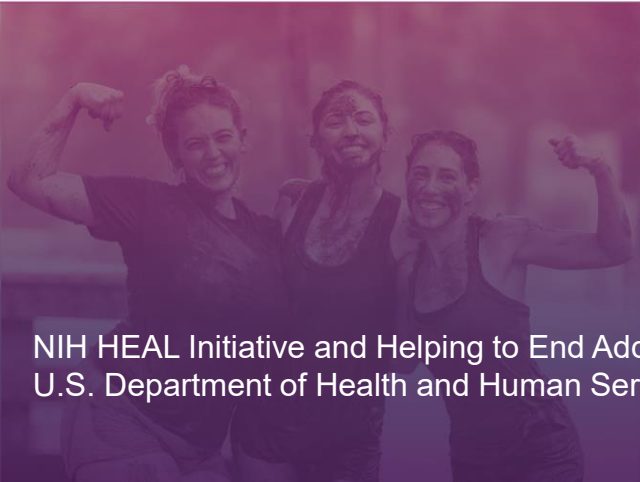




**NIH
HEAL
INITIATIVE**

Jessica Mazerik
HEAL Initiative Data Ecosystem
April 15, 2021



Crisis #1: National Overdose Deaths

Crisis #2: Chronic Pain in the U.S.

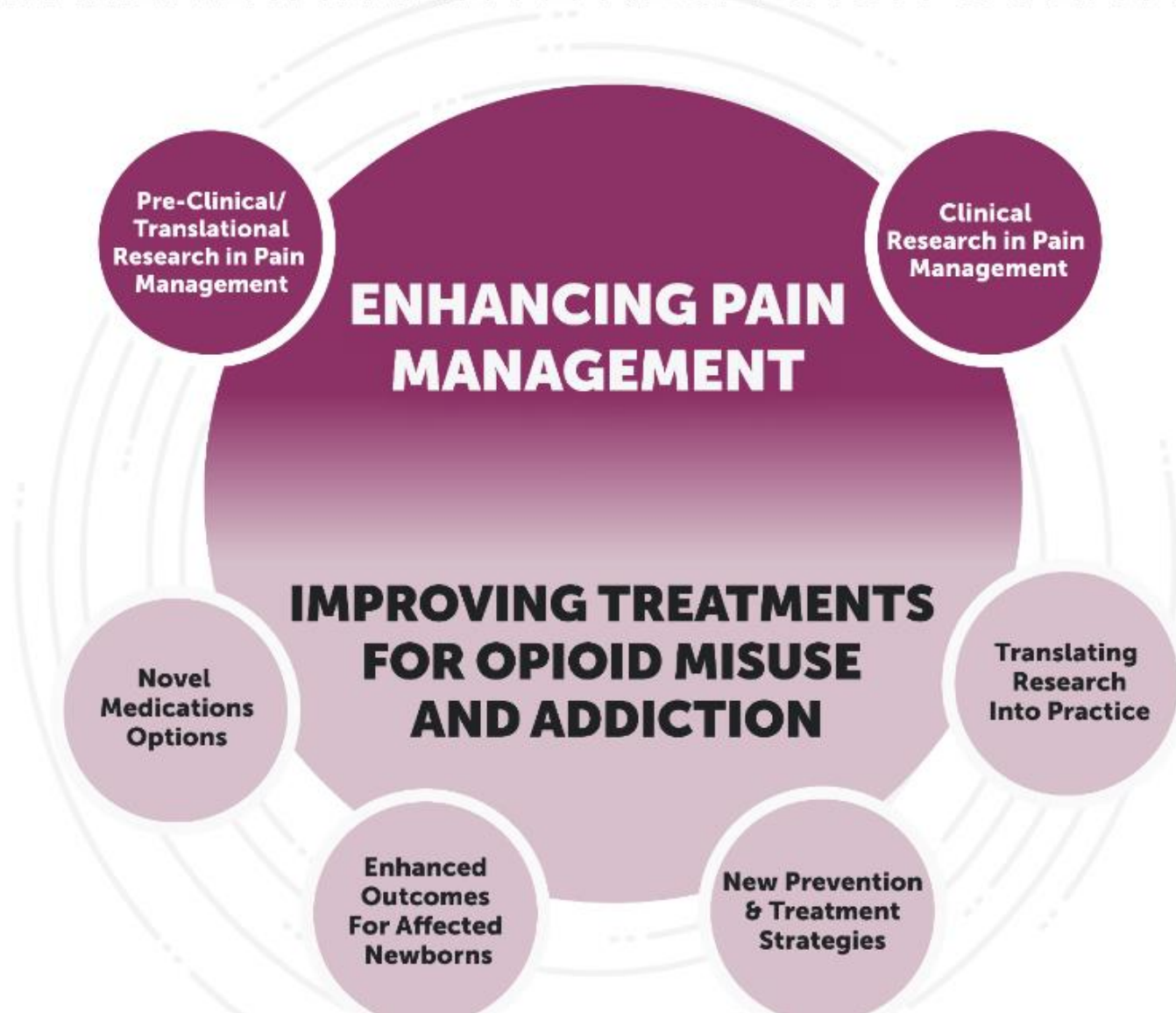
The Response: \$500 million/year Sustained Research Investment

25+ HEAL Research Programs

Prevention – Basic & Translational
Research – Clinical Trials –
Implementation Science



NIH HEAL INITIATIVE RESEARCH OVERVIEW



Why Do we want to Share and Connect HEAL Data?

Goal...

“...addresses the need for researchers, clinicians, and patients to collaborate on sharing their collective data and knowledge about opioid misuse and pain to provide scientific solutions to the opioid crisis...”

And...

- Enable access of HEAL data for various stakeholders through discoverability
- Allow for pan-HEAL program analytics
- Sustainability of HEAL digital assets beyond individual awarded programs
- Serve future research, collaborations, and programs

Making Data *FAIR*

Findable

- have unique identifiers, effectively labeling it within searchable resources.

Accessible

- be easily retrievable via open systems and effective and secure authentication and authorization procedures.

Interoperable

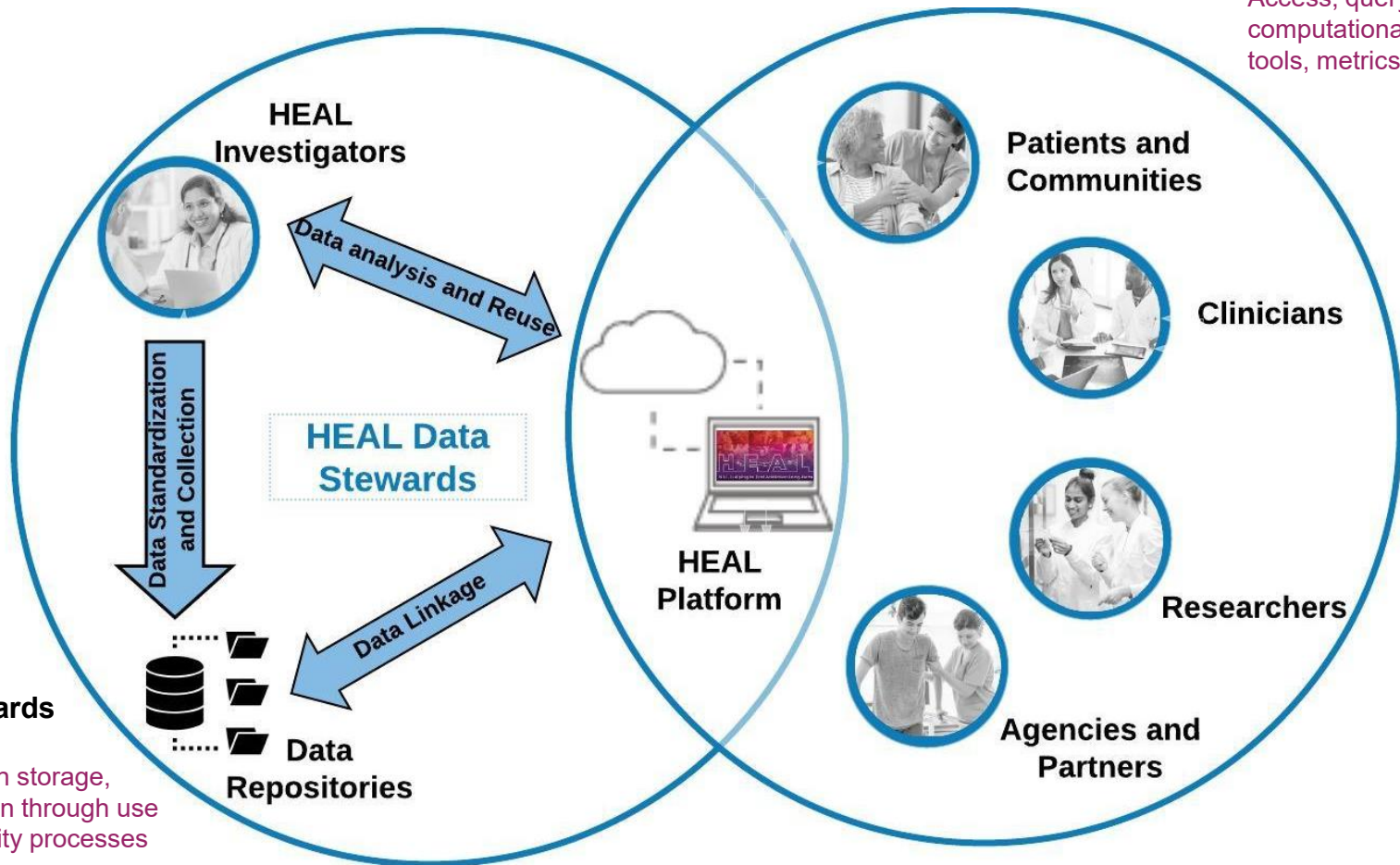
- should “use and speak the same language” via use of standardized vocabularies.

Reusable

- must be adequately described to a new user, have clear information about data-usage licenses, and have a traceable “owner’s manual,” or provenance.

HEAL Data Ecosystem

HEAL Platform
University of Chicago
Access, query,
computational services and
tools, metrics



Data Stewards
RENCI/RTI
Consulting on storage,
harmonization through use
cases, security processes

Meet the HEAL Stewards!

Defining Value and Usability

Platform Use: Identify innovative local strategies to help people misusing opioids

User: Community service organization leader



As a community-based service organization we want to support people misusing opioids in our communities in order to save lives and reduce suffering.

Platform Use: Monitor HEAL pain research and clinical trials results

User: Clinician helping patients manage pain



As a clinician treating patients with chronic pain, I want access to the latest pain research and clinical trial results to identify and track potential new approaches to assist my patients.

Platform Use: Optimize existing medication-based approaches

User: HEAL researcher



As a research expert in opioid misuse and addiction, I want to compare different psychosocial interventions to optimize medication-based treatment approaches for opioid use disorder.

Platform Use: Validate a pain drug target

User: HEAL researcher



As a pain translational researcher, I want to validate a pain drug target in multiple species in order to have a complete evaluation of a possible novel pain drug target.

HEAL Data Ecosystem – Engagement

Broad stakeholder engagement

HEAL PIs, patients & communities, clinicians, agencies & partners, researchers, program staff



Work amongst the HEAL Data Ecosystem team

HEAL Platform Developers, HEAL Data Stewards, HEAL Researchers

Understand stakeholder needs!

- How will you use it?
- What questions will you ask?
- What will add value?
- Which analyses tools?
- How should it look/feel?

Incorporate Feedback

- Implement metadata and data standards
- Incorporate design elements and features
- Add tools
- Improve the look & usability

Upcoming Workshop: April 20

*Creating a Community: HEAL Data Ecosystem
Virtual Workshop*

- <https://cvent.me/7yPnKL>



NIH • Helping to End Addiction Long-term

www.heal.nih.gov