

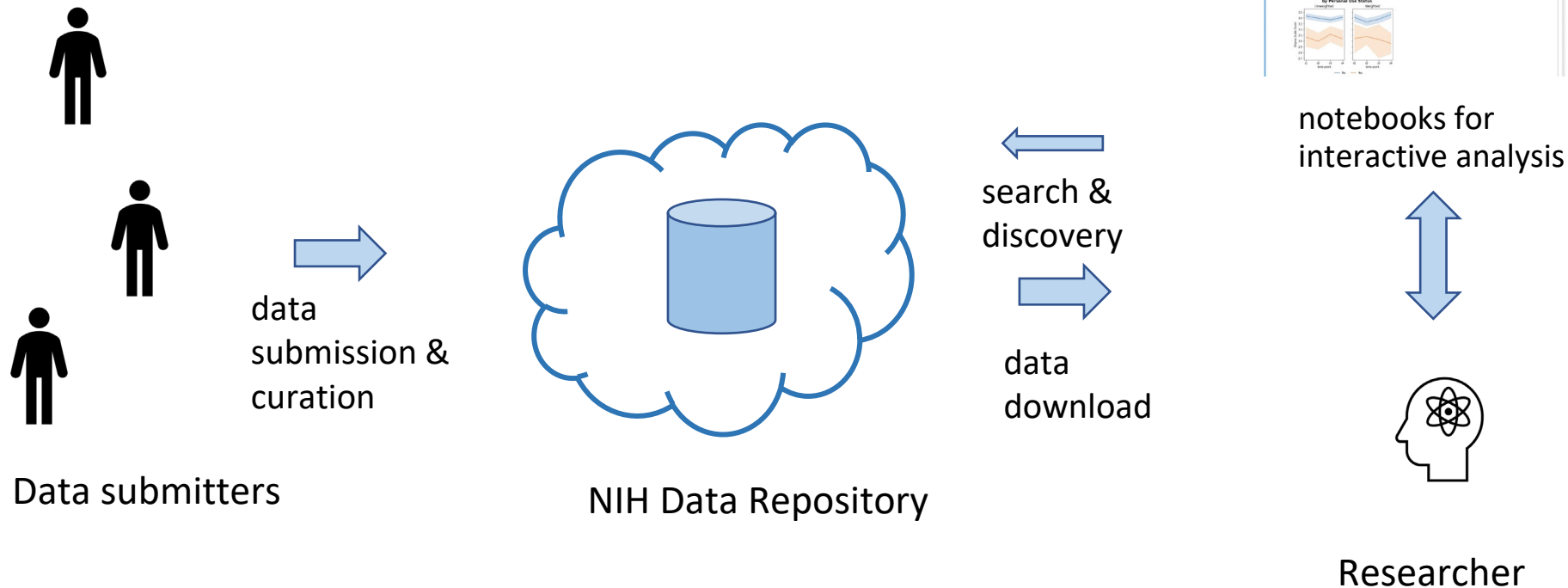
# HEAL Data Platform

Robert L. Grossman

L. Philip Schumm



# The Standard Model for Data Sharing



# Evolution of Data Platforms

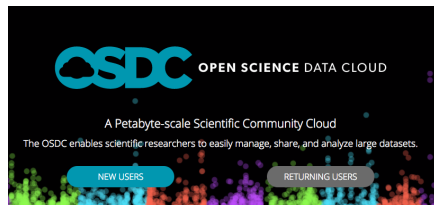
## Research Project with Download



## Databases (1982)

- Data repositories
- Download data

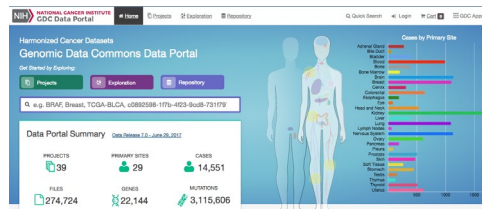
## Research Project with Cloud Computing



## Data Clouds (2010)

- Support for large-scale data and computing

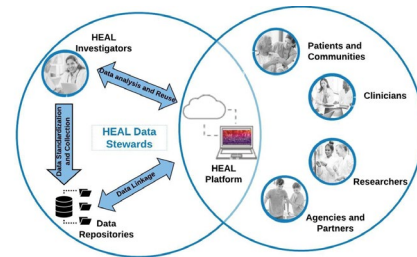
## Single Research Community



## Data Commons (2016)

- Common data models
- Core data services
- Governance
- Workspaces

## Multiple Research Communities



## Data Ecosystems (2020)

Source: Grossman, Robert L. "Data lakes, clouds, and commons: A review of platforms for analyzing and sharing genomic data." Trends in Genetics 35, no. 3 (2019): 223-234.

# Data Ecosystems

## Research Community

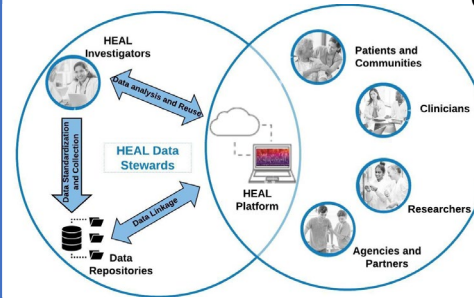
## Research Project



## Data Commons (2016)

## Data Clouds (2010)

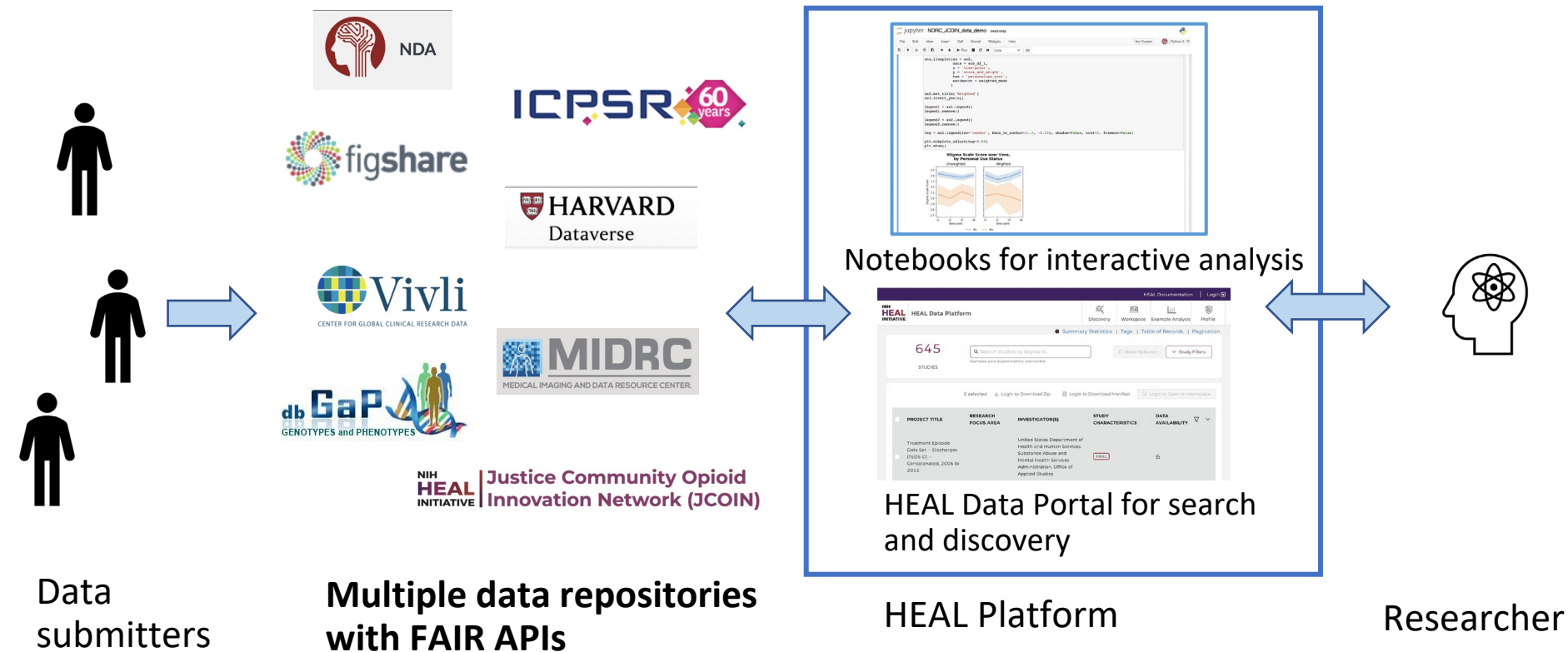
## Multiple Research Communities



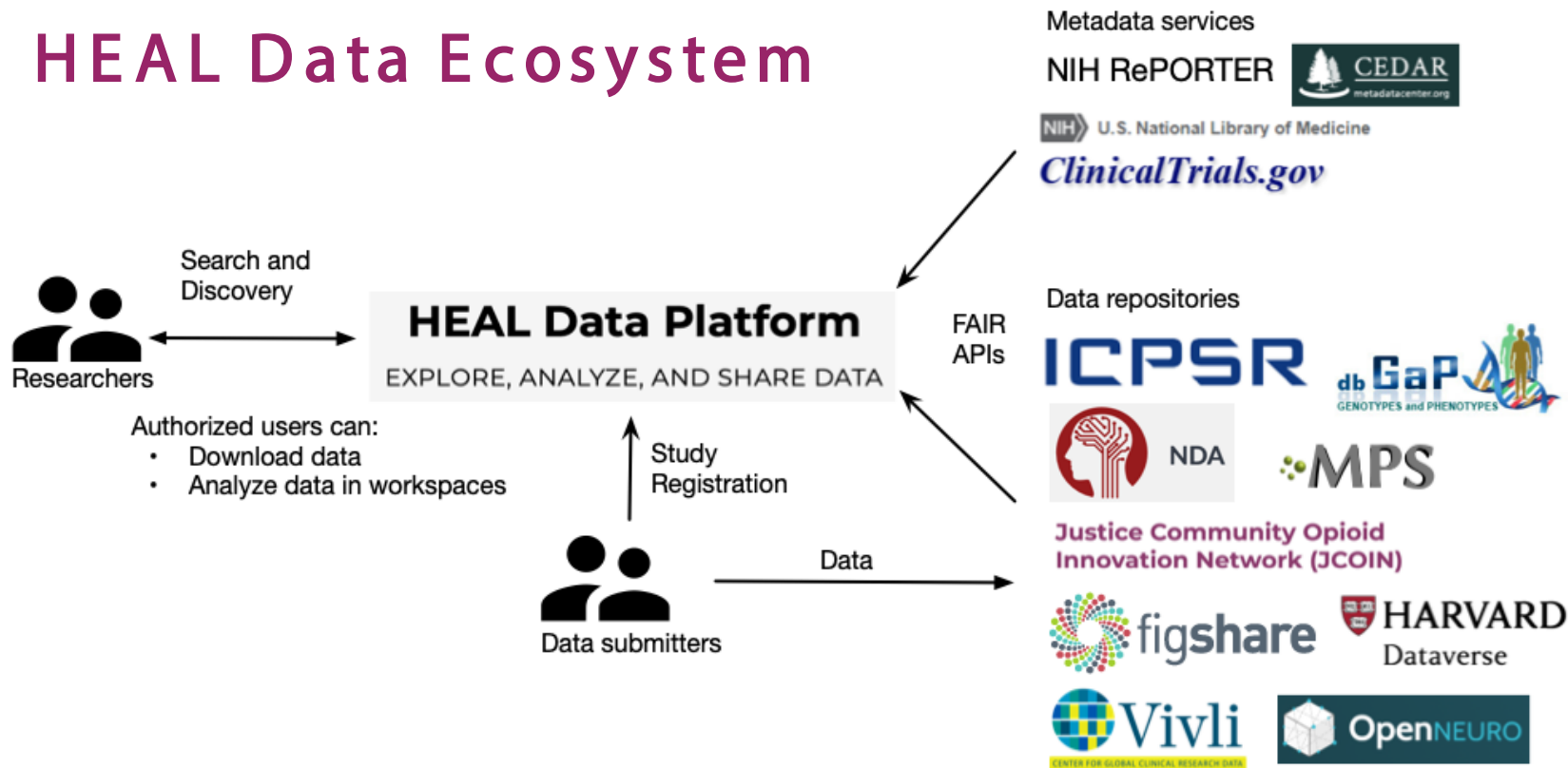
## Data Ecosystems (2020)

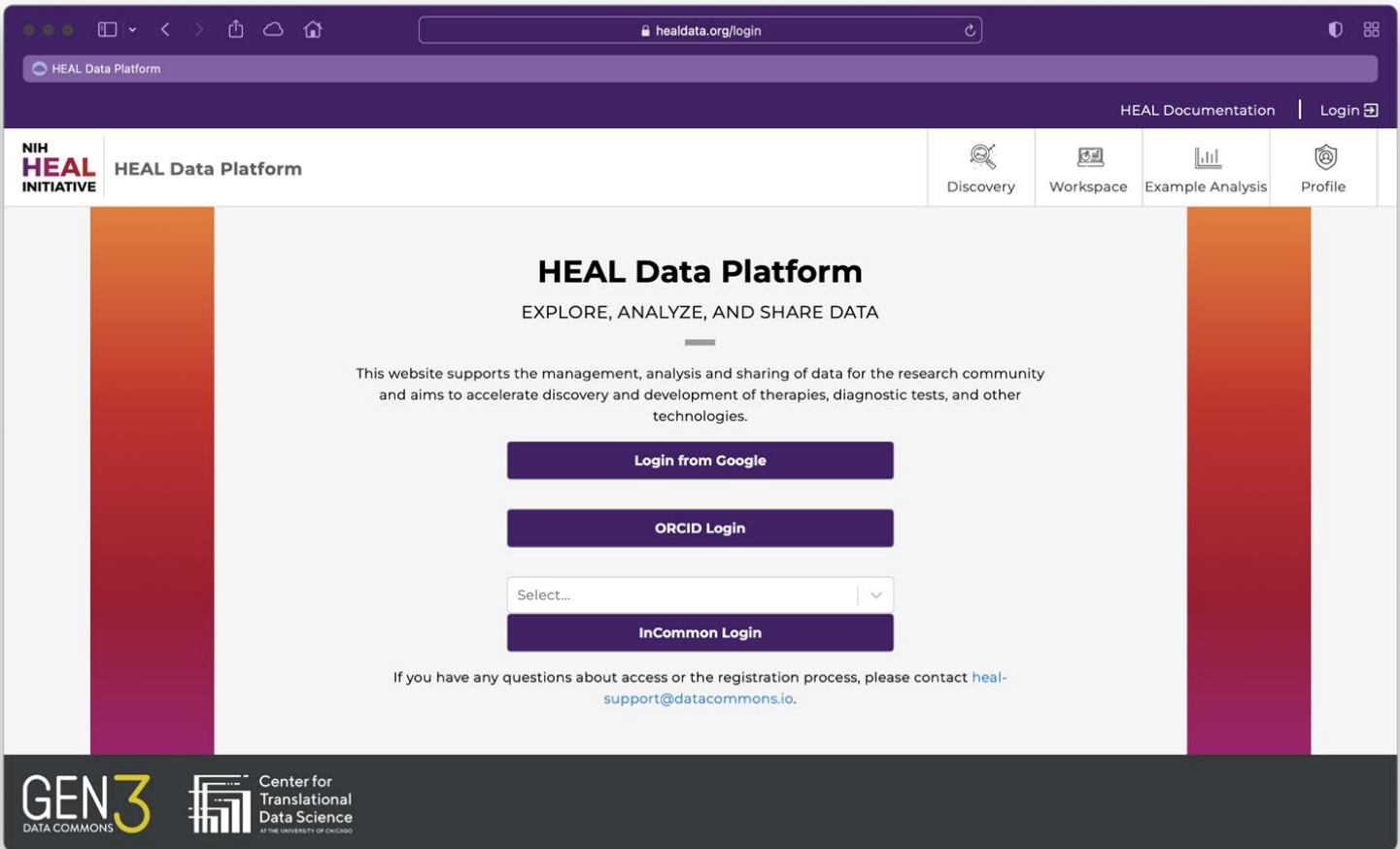
- aka a “data mesh”
- Data ecosystems consisting of multiple data repositories, computational resources, knowledge bases, notebooks, & applications across multiple disciplines that can interoperate
- Hybrid governance model
- Services to support multiple data models

# The HEAL Platform is a Data Ecosystem (aka a Data Mesh)



# HEAL Data Ecosystem





HEAL Data Platform

Discovery

Workspace

Example Analysis

Profile

[Summary Statistics](#) | [Tags](#) | [Table of Records](#) | [Pagination](#)

Q stigma

Examples: pain, buprenorphine, intervention

Community

Subject Characteristics

Intervention/Treatment

Substance Use

Data Resources

Study Design

Pain

Data Type

Reset Selection

Study Filters

1

STUDIES

0 selected

Login to Download Zip

Login to Download Manifest

Login to Open In Workspace

PROJECT TITLE	RESEARCH FOCUS AREA	INVESTIGATOR(S)	STUDY CHARACTERISTICS	DATA AVAILABILITY
<input type="checkbox"/> Methodology and Advanced Analytics Resource Center	Translation of Research to Practice for the Treatment of Opioid Addiction	Schneider, John; Pollack, Harold	<div> <div>Community</div> <div>Opioid Use</div> <div>Practice</div> <div>Quality</div> <div>Racial and Ethnic Populations</div> <div>Justice-involved Populations</div> <div>Observational</div> <div>Clinical</div> <div>Pain Treatment</div> <div>JCOIN</div> </div>	<input type="checkbox"/>

Abstract: Tracking changes in stigma associated with OUD is important, for as stigma intensifies over time it might make it more difficult to find positive treatment effects in JCOIN. Given the critical importance of public opinion towards policy making and approaches used in the justice system, this project will measure public support for OUD treatment in the general public, assess stigma associated...



HEAL Data Platform

NIH  
HEAL  
INITIATIVE

HEAL Data Platform

1

STUDIES

Q stigma

Examples: pain, buprenorphine, intervention

Community X

Study Design

Pain

Data Type

0 selected

Log

PROJECT TITLE

RESEARCH FOCUS AREA

Methodology and Advanced Analytics Resource Center

Translation of Research to Practice for the Treatment of Opioid Addiction

Abstract: Tracking changes in stigma associated with OUD is important, for as stigma intensifies over time, the importance of public opinion towards policy making and approaches used in the justice system, this project

BACK

Permalink

Methodology and Advanced Analytics Resource Center

You have access to this study.

PROJECT NUMBER

1U2CDA050098-01.a

RESEARCH FOCUS AREA

Translation of Research to Practice for the Treatment of Opioid Addiction

RESEARCH PROGRAM

Justice Community Opioid Innovation Network

RESEARCH QUESTION

Research questions: (1) What level of stigma does the general public attribute to individuals with an OUD? (2) What is the general public knowledge base and awareness of addiction and opioid treatment? (3) What is the public attitudes towards OUD, OUD treatment, and how does this vary by knowing individuals who have overdosed or social distance? (4) What is the public perceptions of criminality around OUD and appropriateness of justice interventions (incarceration/punitive and/or community/rehab)? We will also have demographic data on each study participant.

INSTITUTION(S)

University Of Chicago/NORC

LOCATION

Chicago, IL

INVESTIGATOR(S)

Schneider, John; Pollack, Harold

ADMINISTERING IC(S)

NIDA

YEAR GRANT AWARDED

2019

STUDY TYPE

repeated cross-sectional survey

STUDY NAME

Amerispeak Brief Stigma Survey (JCOIN 026)

STUDY DESCRIPTION

Observational

NUMBER OF SUBJECTS

1000

NUMBER OF SITES

1

PROTOCOL NAME

JCOIN 026: Amerispeak Brief Stigma Survey

HEAL Data Platform

Discovery
Workspace
Example Analysis
Profile

Summary Statistics
Tags
Table of Records
Pagination

Examples: pain, buprenorphine, intervention

1
STUDIES

Community x
Subject Characteristics
Intervention/Treatment
Substance Use
Data Resources

2 selected
Login to Download Zip
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<input checked="" type="checkbox"/> Methodology and Advanced Analytics Resource Center	Translation of Research to Practice for the Treatment of Opioid Addiction	Schneider, John; Pollack, Harold	<div> Community Opioid Use Practice Quality Racial and Ethnic Populations Justice-involved Populations Observational Clinical Pain Treatment JCOIN </div>	<input type="checkbox"/>

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HEAL Data Platform

HEAL Documentation | philschumm@gmail.com | Logout

Discovery | Workspace | Example Analysis | **Profile**

### Link accounts from external data resource(s)

**JCOIN Google Login**

IDP: jcoin-google

Provider URL: <https://jcoin.datacommons.io>

Status: not authorized

Authorize JCOIN Google Login

**FAIR Repository Google Login**

IDP: externaldata-google

Provider URL: <https://externaldata.healdata.org>

Status: not authorized

Authorize FAIR Repository Google Login

Create API key

### You have the following API key(s)

API key(s)	Expires	
941edbd6-9c78-45aa-a8be-ebb89c9a0903	11/9/2021 5:52:31 PM	Delete

healdata.org/identity

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HEAL Documentation | philschumm@gmail.com | Logout

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Discovery Workspace Example Analysis Profile

### Link accounts from external data resource(s)

**JCOIN Google Login**

IDP: jcoin-google

Provider URL: <https://jcoin.datacommons.io>

Status: expires in 29 days

Refresh JCOIN Google Login

**FAIR Repository Google Login**

IDP: externaldata-google

Provider URL: <https://externaldata.healdata.org>

Status: not authorized

Authorize FAIR Repository Google Login

Create API key

### You have the following API key(s)

API key(s)	Expires	
941edbd6-9c78-45aa-a8be-ebb89c9a0903	11/9/2021 5:52:31 PM	Delete

Discovery

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1

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Pain

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<input checked="" type="checkbox"/> <div>Methodology and Advanced Analytics Resource Center</div>	<div>Translation of Research to Practice for the Treatment of Opioid Addiction</div>	<div>Schneider, John; Pollack, Harold</div>	<div> <div>Community</div> <div>Opioid Use</div> <div>Practice</div> <div>Quality</div> <div>Racial and Ethnic Populations</div> <div>Justice-involved Populations</div> <div>Observational</div> <div>Clinical</div> <div>Pain Treatment</div> <div>JCOIN</div> </div>	<div> <div> <div></div> </div> </div>

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Discovery
Workspace
Example Analysis
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## Static HEAL Jupyter Notebooks

The Jupyter notebooks contained in this notebook viewer pull data from various sources to generate and output useful tables, charts, graphs, and models. Each notebook is static, meaning the data being used by the notebooks is not updated in real time. These notebooks are also available in the Gen3 Workspace.

### BACPAC Synthetic Data Analysis

In this Jupyter notebook, we used synthetic data of the BACPAC study as an example to demonstrate how to navigate datasets within the workspace in HEAL and conduct data analysis using Python libraries.

### JCOIN Tracking Opioid Stigma

In this Jupyter notebook, we used the JCOIN-MAARC (Justice Community Opioid Innovation Network - Methodology and Advanced Analytics Resource Center) Survey Core Survey Project 1/4 to track stigma related to Opioid Use Disorder (OUD) and public attitudes towards persons with OUD as well as how treatment of/for persons with OUD may impact the effect of OUD interventions.

### Opioid Prevalence And Overdoses

In this Jupyter notebook, we used the CDC WONDER, DEA ARCOS, and PDAPS datasets to demonstrate how multiple datasets may be utilized within the workspace in HEAL.

# Workspaces

- Secure use of data leveraging cloud services
- Access to common software and specialized tools
- STRIDES
- Collaboration
- Replicability

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HEAL Data Platform

Discovery Workspace Example Analysis Profile

▼ User Pay Model Information


Pay Model Name	AWS Account ID	AWS Account Region
healworkspaces	252835817747	us-east-1



**(Generic) Jupyter Lab Notebook with R Kernel**

1.0CPU, 2Gi memory


Launch



**(Generic, Limited Gen3-licensed) Stata Notebook**

1.0CPU, 2Gi memory


Launch



**(Generic, User-licensed) Stata Notebook**

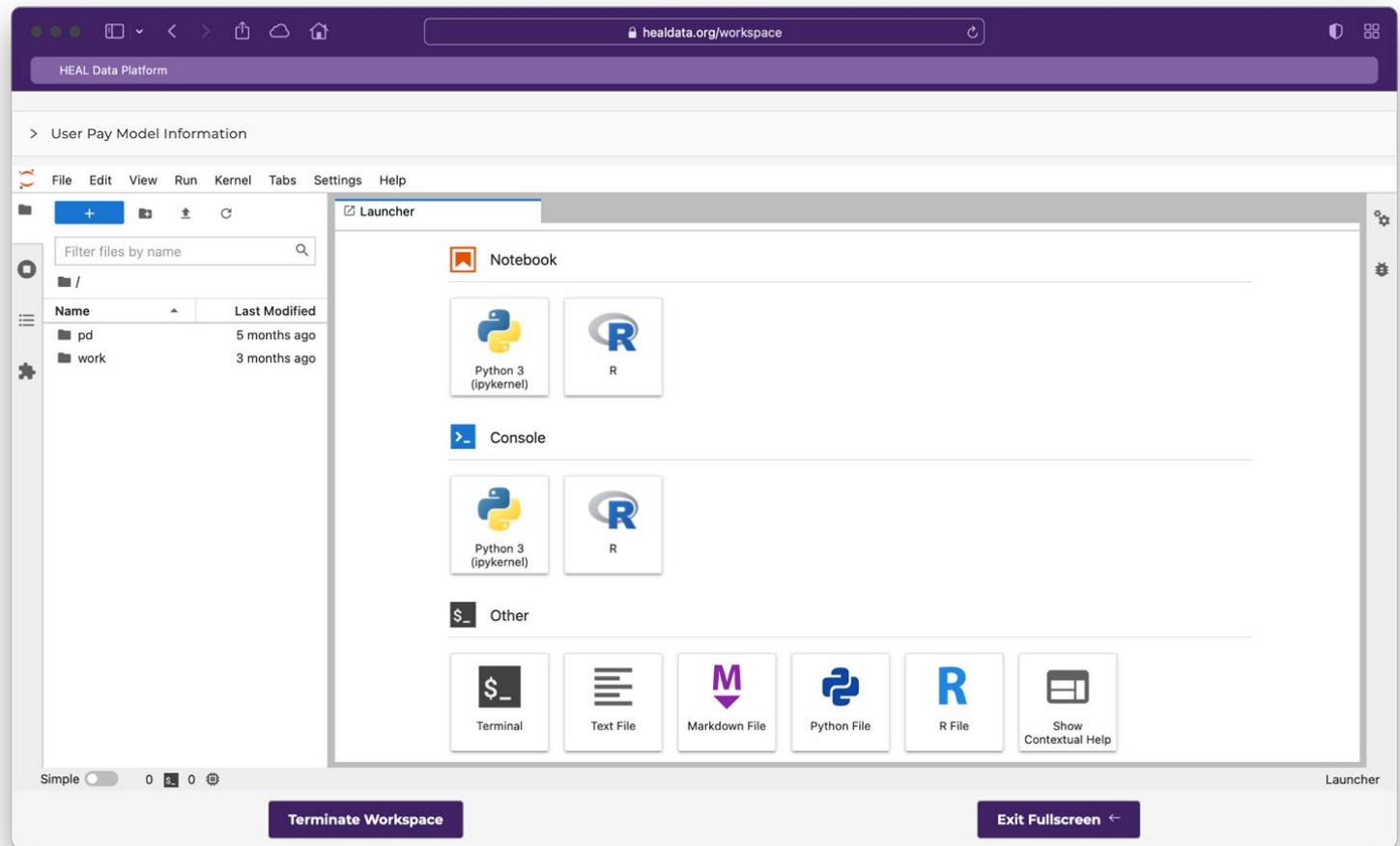
1.0CPU, 2Gi memory

Launch



**(Tutorials) Example**

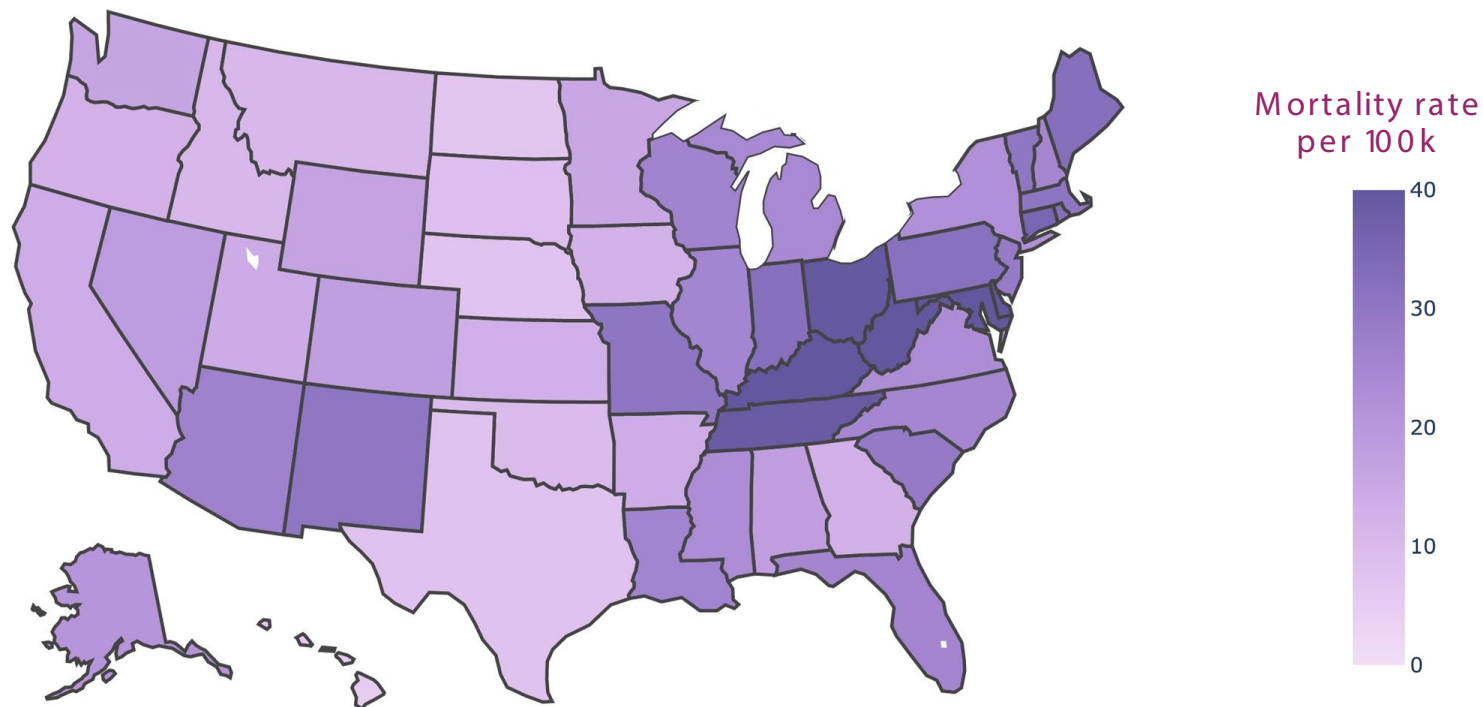




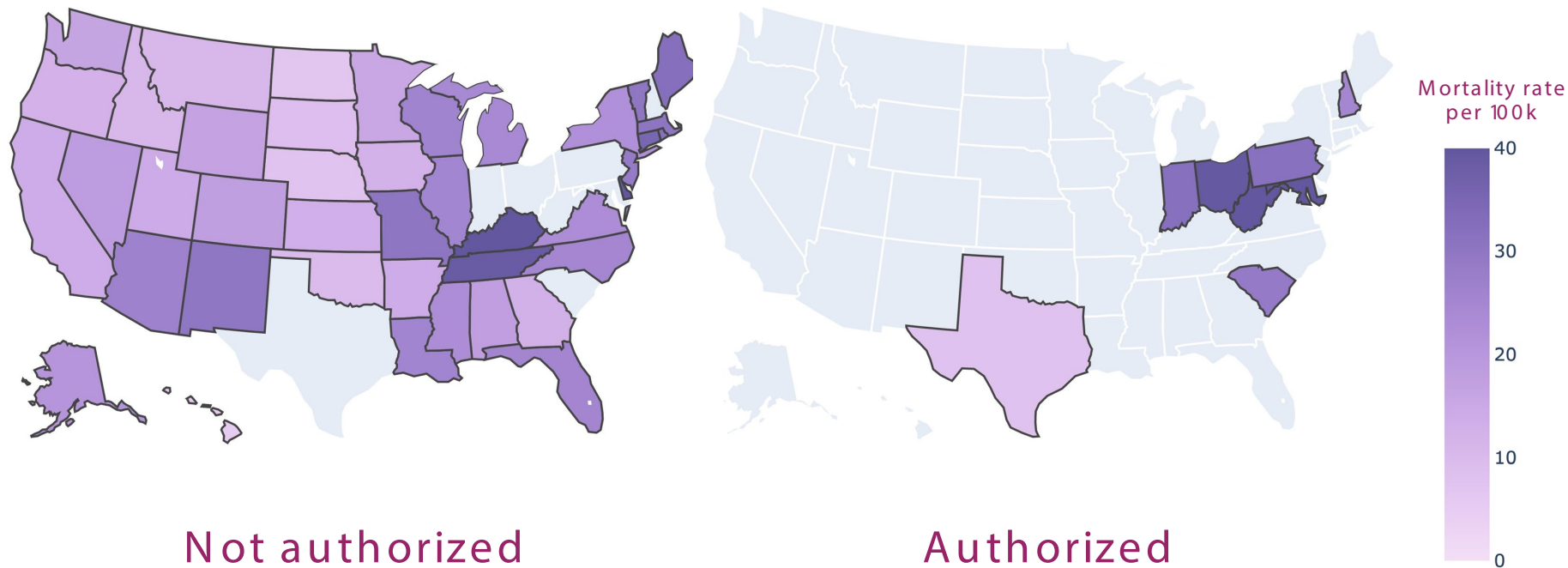
# Combining datasets (example)

- CDC Wide-ranging Online Data for Epidemiologic Research (CDC WONDER) Mortality Multiple Cause-of-Death Public Use Record
- Prescription Drug Abuse Policy System (PDAPS)
  - Increasing Access to Buprenorphine and Methadone During COVID-19
  - COVID-19 Mitigation Laws at State Correctional Facilities Relating to Opioid Use Disorder Treatment
  - COVID-19 State Medicaid Waivers for Substance Use Disorder Treatment

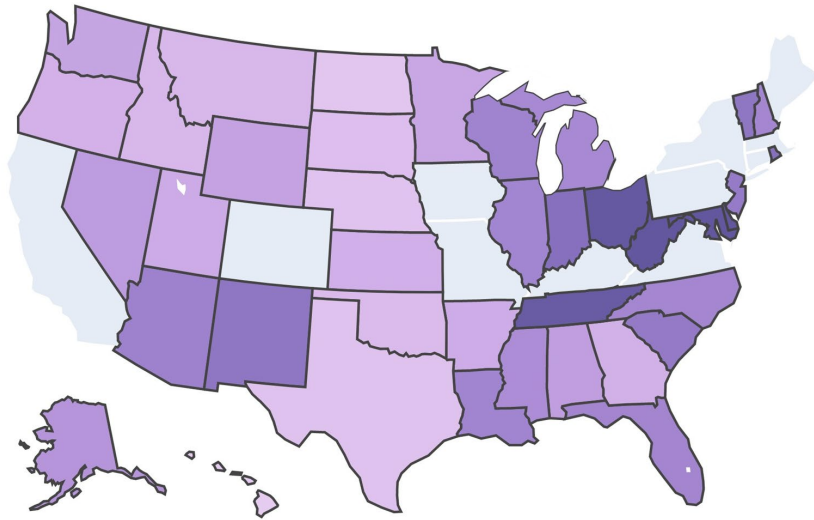
# CDC Wonder: 2020 Opioid Overdose Mortality



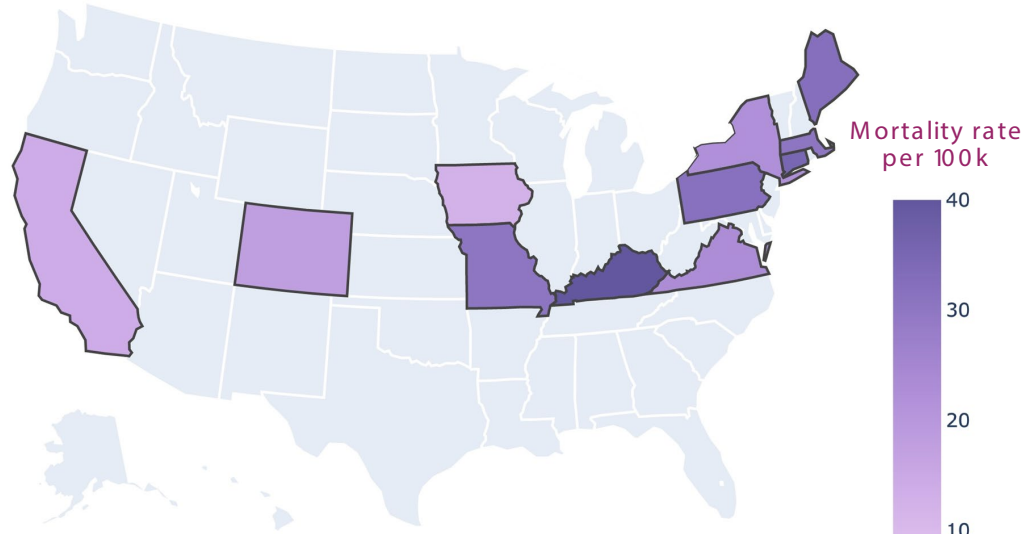
# PDAPS: Telehealth for buprenorphine or methadone



## PDAPS: Correctional facilities modified MOUD policy for COVID-19

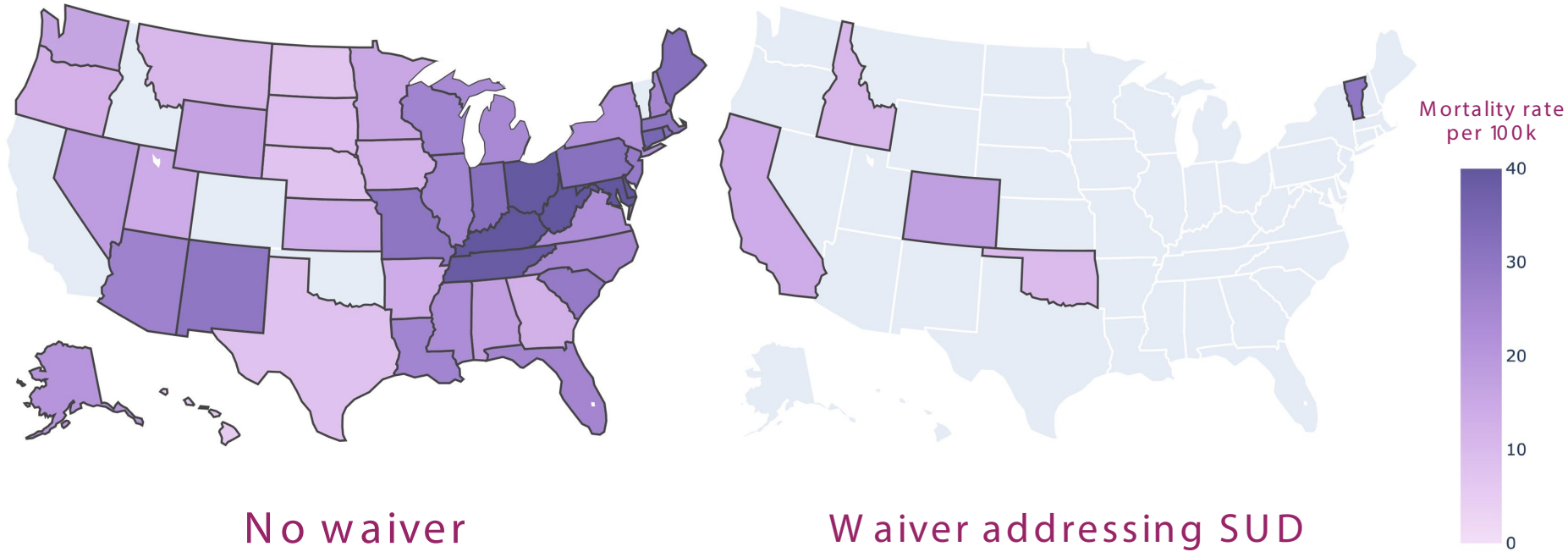


## Did not alter policy



## Altered policy

# PDAPS: Approved Medicaid Section 1115 waiver addressing SUD treatment



# Registering Your Study on the Platform

- HEAL-funded studies already discoverable on the Platform
- Registration links study to external sources of study metadata
- After data submitted to repository, link study to data
- Early registration available soon to investigators ready to share data