HEAL Data Platform

Robert L. Grossman

L. Philip Schumm

The Standard Model for Data Sharing

notebooks for interactive analysis

search & discovery

data submission & curation

data download

Data submitters

NIH Data Repository

Researcher

Evolution of Data Platforms

Research Project with Download

Databases
(1982)

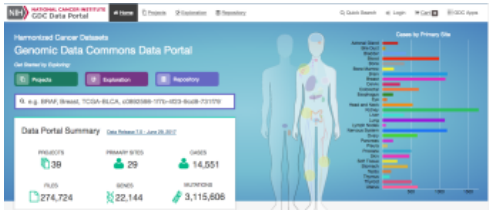
- Data repositories
- Download data

Research Project with Cloud Computing

Data Clouds
(2010)

- Support for large-scale data and computing

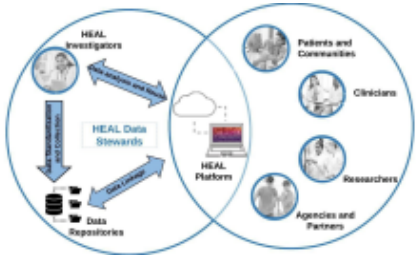
Single Research Community



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

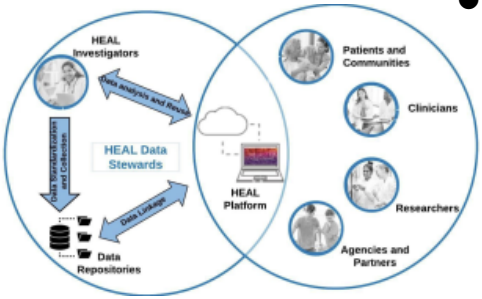
Research Project

Data Clouds
(2010)

Research Community

Data Commons
(2016)

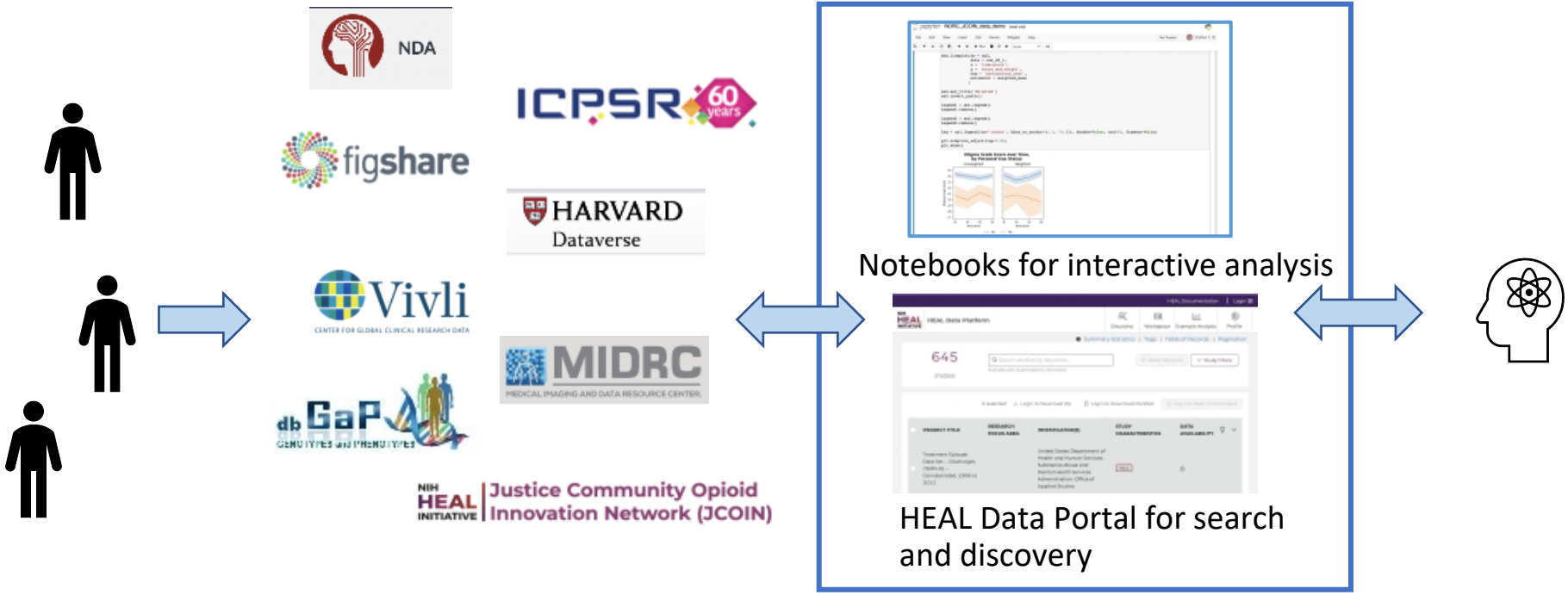
Multiple Research Communities



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)



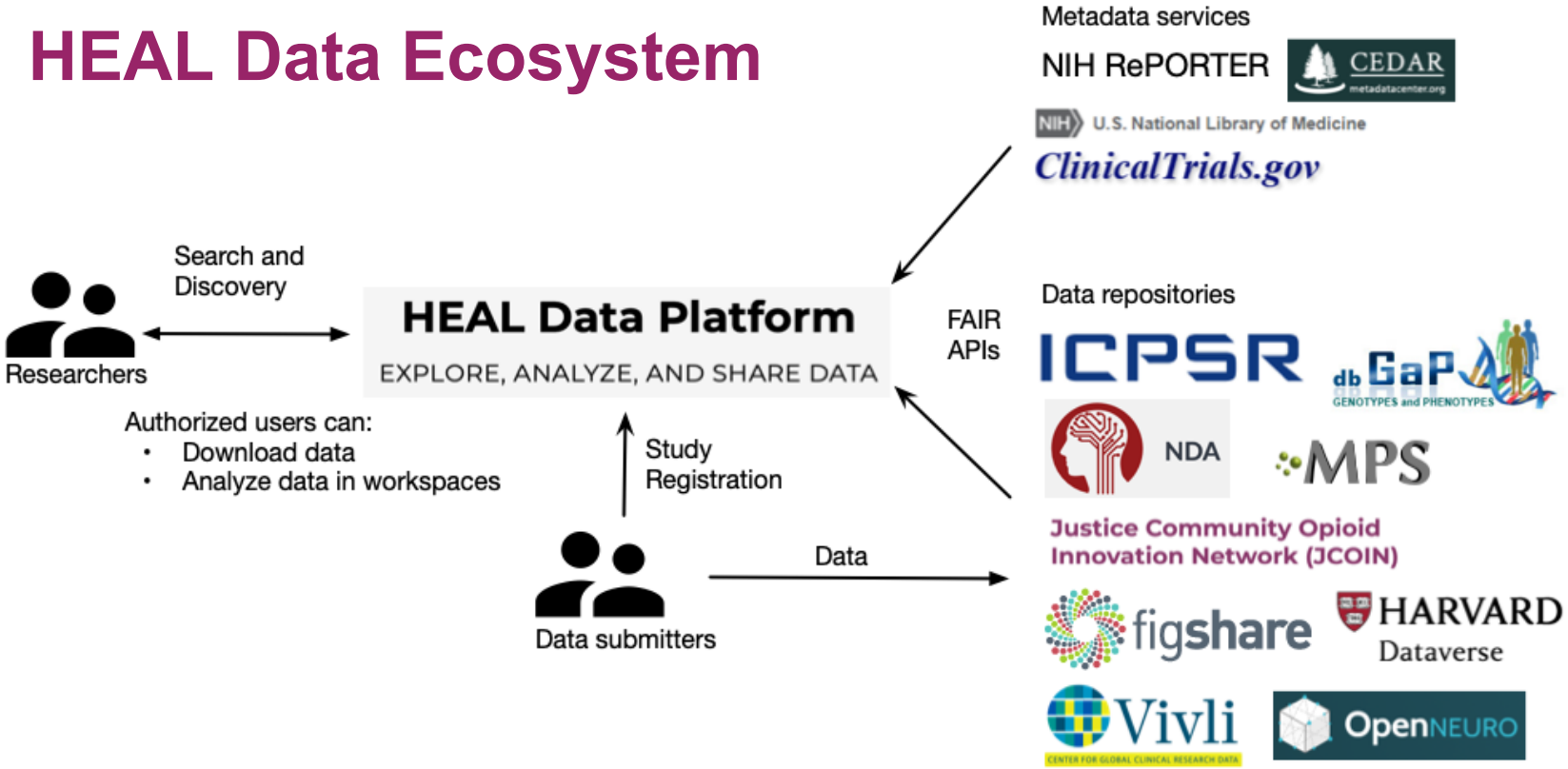
Data submitters

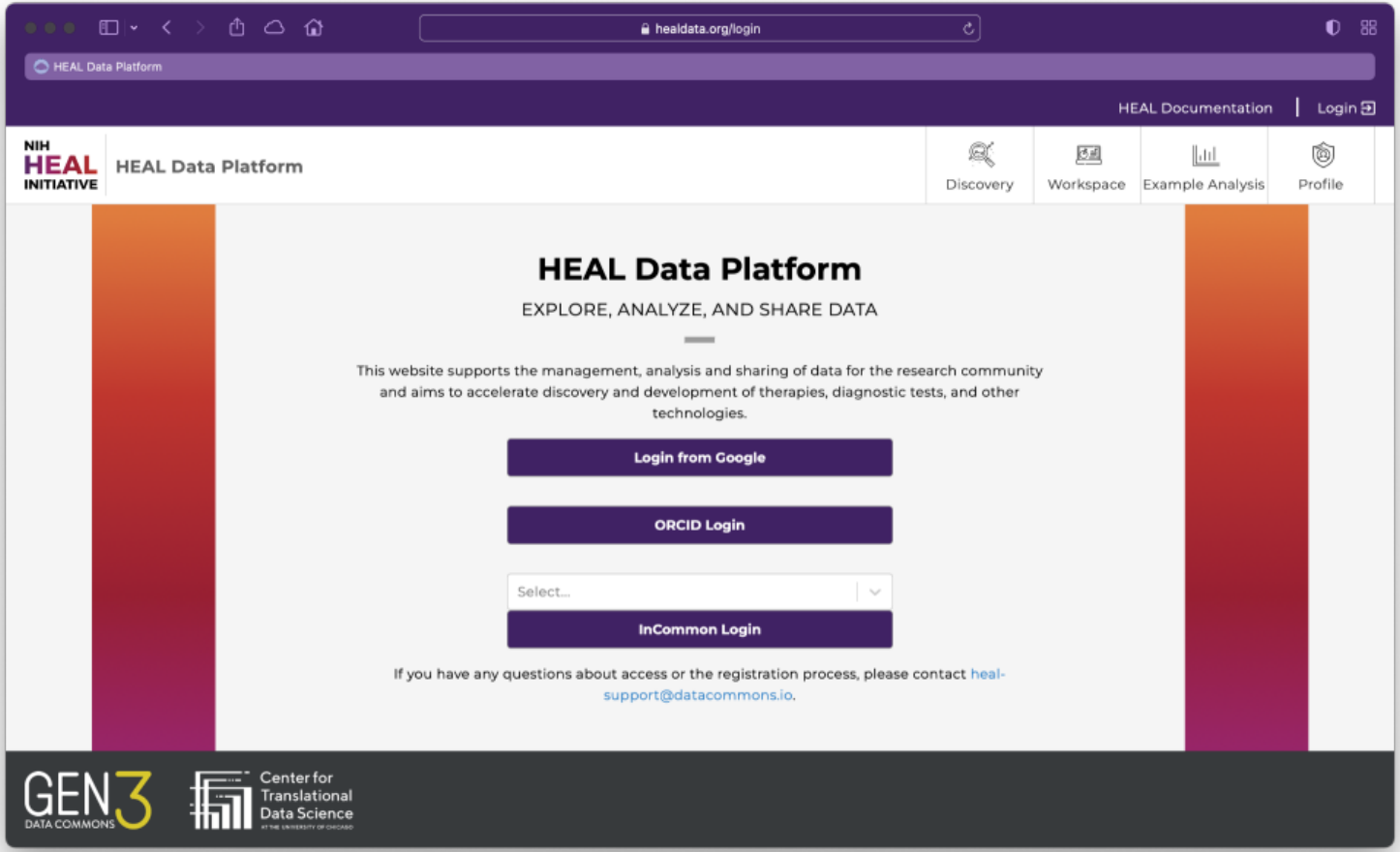
Multiple data repositories with FAIR APIs

HEAL Platform

Researcher

HEAL Data Ecosystem

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Example Analysis
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HEAL Data Platform
EXPLORE, ANALYZE, AND SHARE DATA
This website supports the management, analysis and sharing of data for the research community and aims to accelerate discovery and development of therapies, diagnostic tests, and other technologies.
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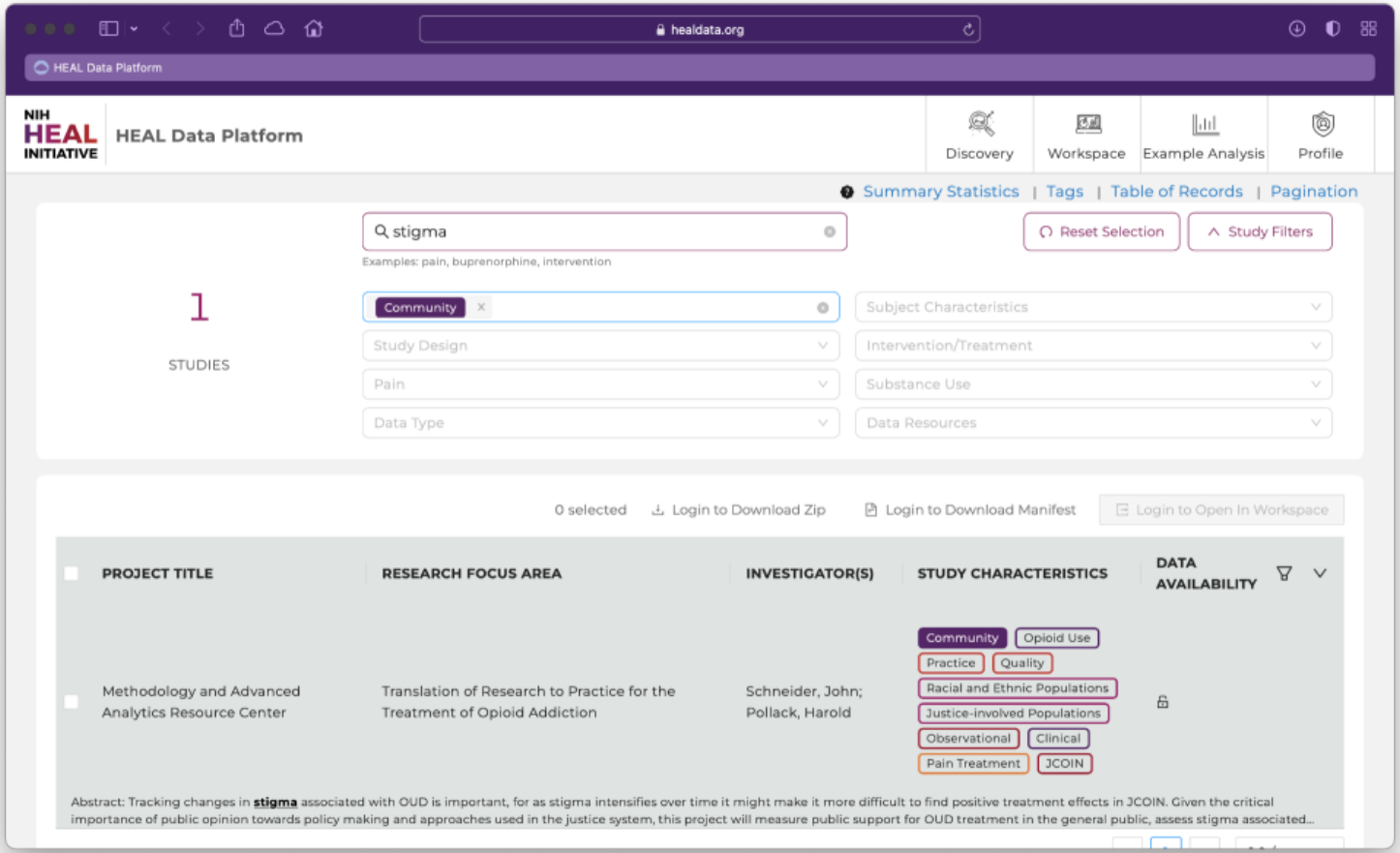
InCommon Login
If you have any questions about access or the registration process, please contact heal-support@datacommons.io.
GEN3 DATA COMMONS
Center for Translational Data Science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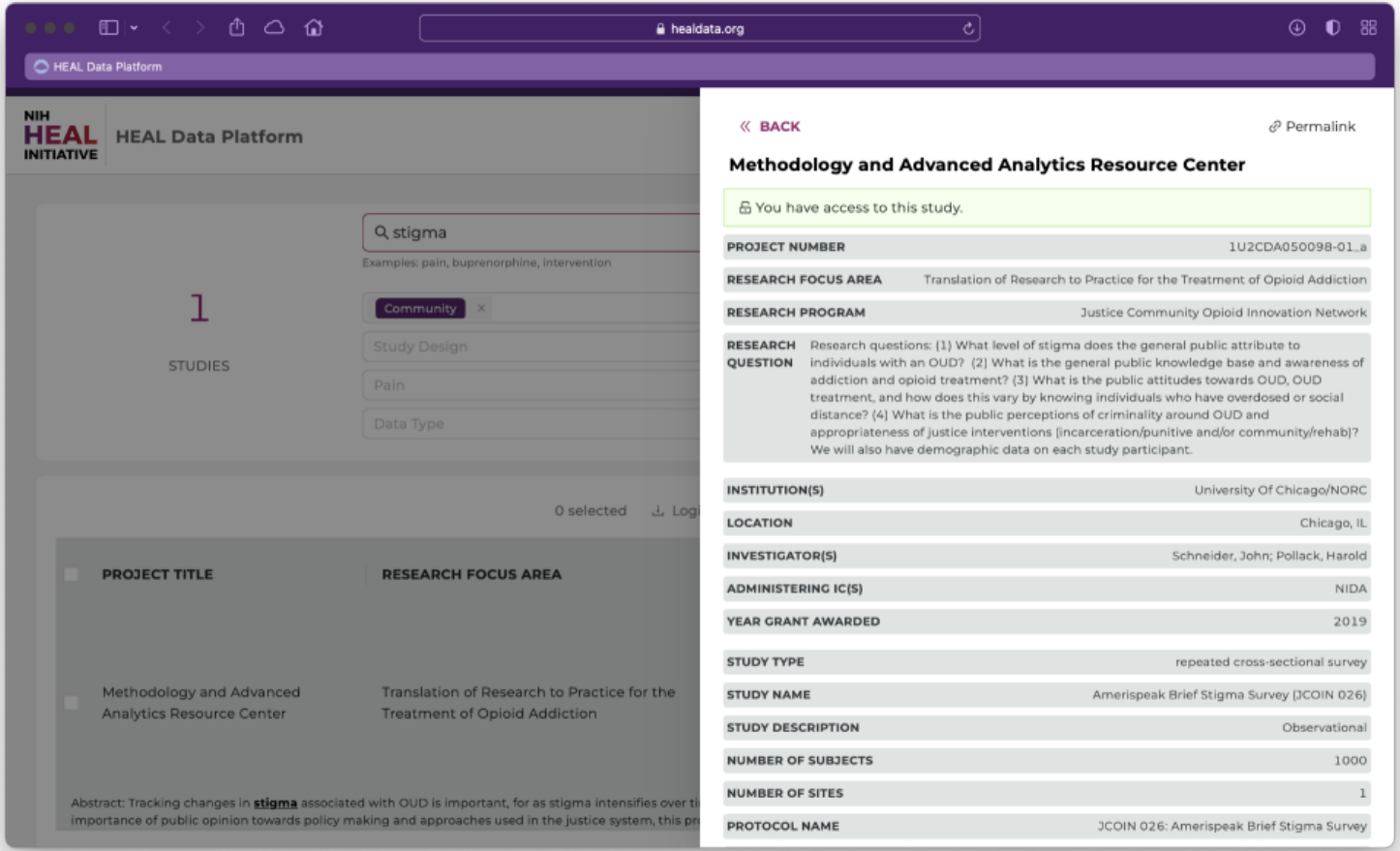
Summary Statistics | Tags | Table of Records | Pagination
stigma
Examples: pain, buprenorphine, intervention
Reset Selection
Study Filters
1
STUDIES
Community
Subject Characteristics
Study Design
Intervention/Treatment
Pain
Substance Use
Data Type
Data Resources
0 selected
Login to Download Zip
Login to Download Manifest
Login to Open In Workspace
PROJECT TITLE
RESEARCH FOCUS AREA
INVESTIGATOR(S)
STUDY CHARACTERISTICS
DATA AVAILABILITY
Methodology and Advanced Analytics Resource Center
Translation of Research to Practice for the Treatment of Opioid Addiction
Schneider, John; Pollack, Harold
Community
Opioid Use
Practice
Quality
Racial and Ethnic Populations
Justice-involved Populations
Observational
Clinical
Pain Treatment
JCOIN
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...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stigma
Examples: pain, buprenorphine, intervention
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STUDIES
Community
Study Design
Pain
Data Type
0 selected
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Methodology and Advanced Analytics Resource Center
Translation of Research to Practice for the Treatment of Opioid Addiction
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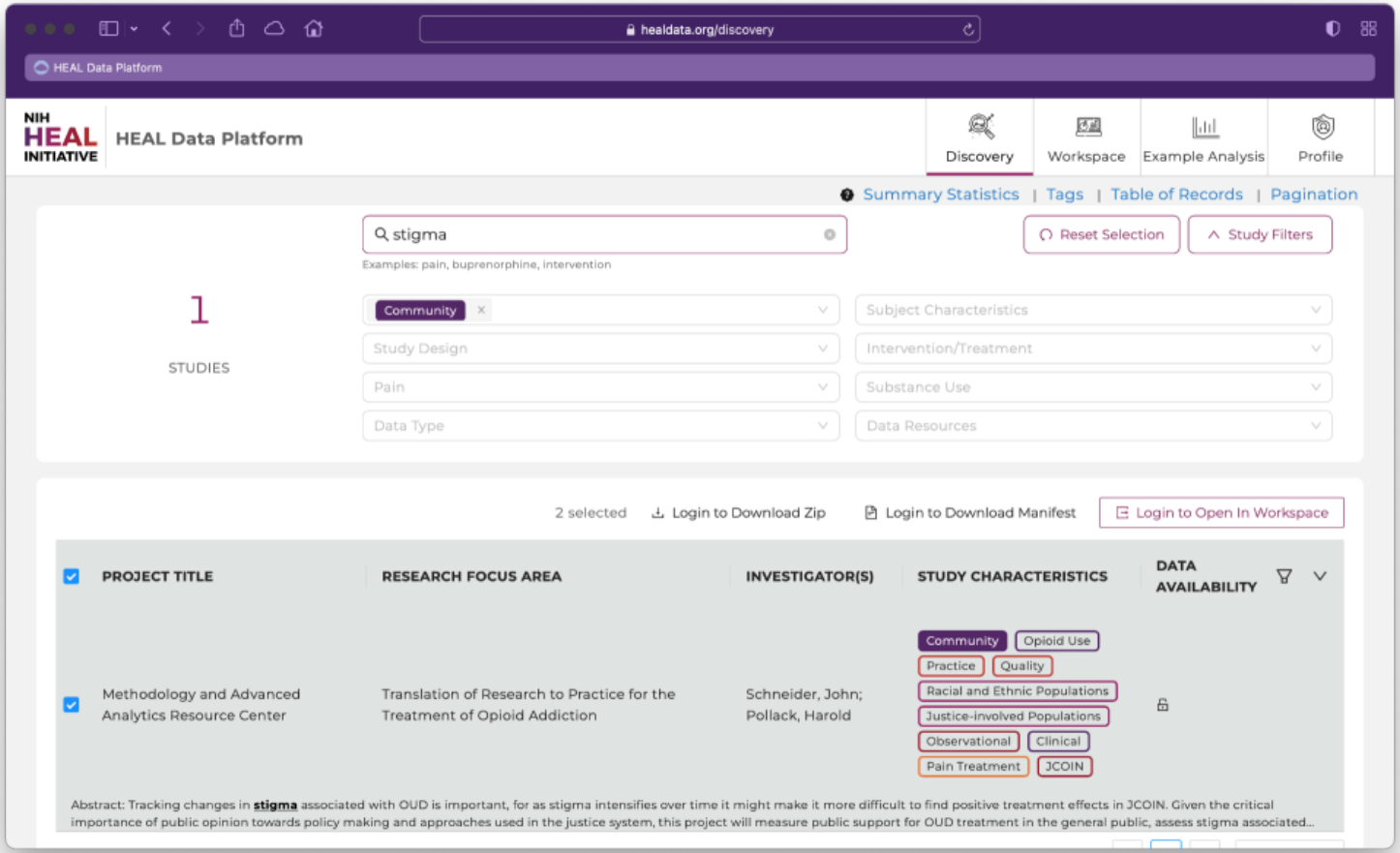
importance of public opinion towards policy making and approaches used in the justice system, this pr
BACK
Permalink
Methodology and Advanced Analytics Resource Center
You have access to this study.
PROJECT NUMBER 1U2CDA050098-01_a
RESEARCH FOCUS AREA Translation of Research to Practice for the Treatment 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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Summary Statistics | Tags | Table of Records | Pagination
stigma
Examples: pain, buprenorphine, intervention
Reset Selection
Study Filters
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STUDIES
Community
Subject Characteristics
Study Design
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Pain
Substance Use
Data Type
Data Resources
2 selected
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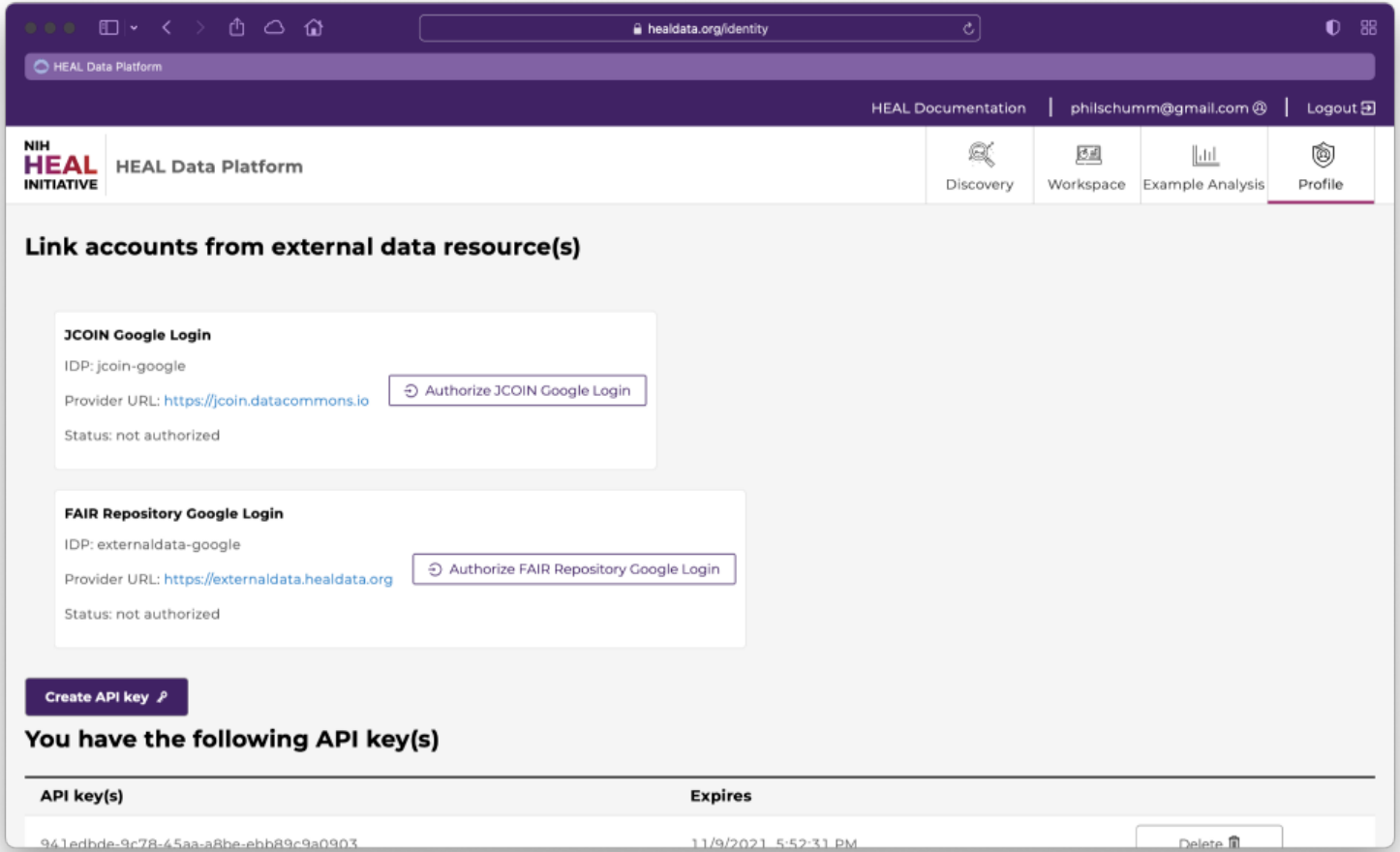
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philschumm@gmail.com
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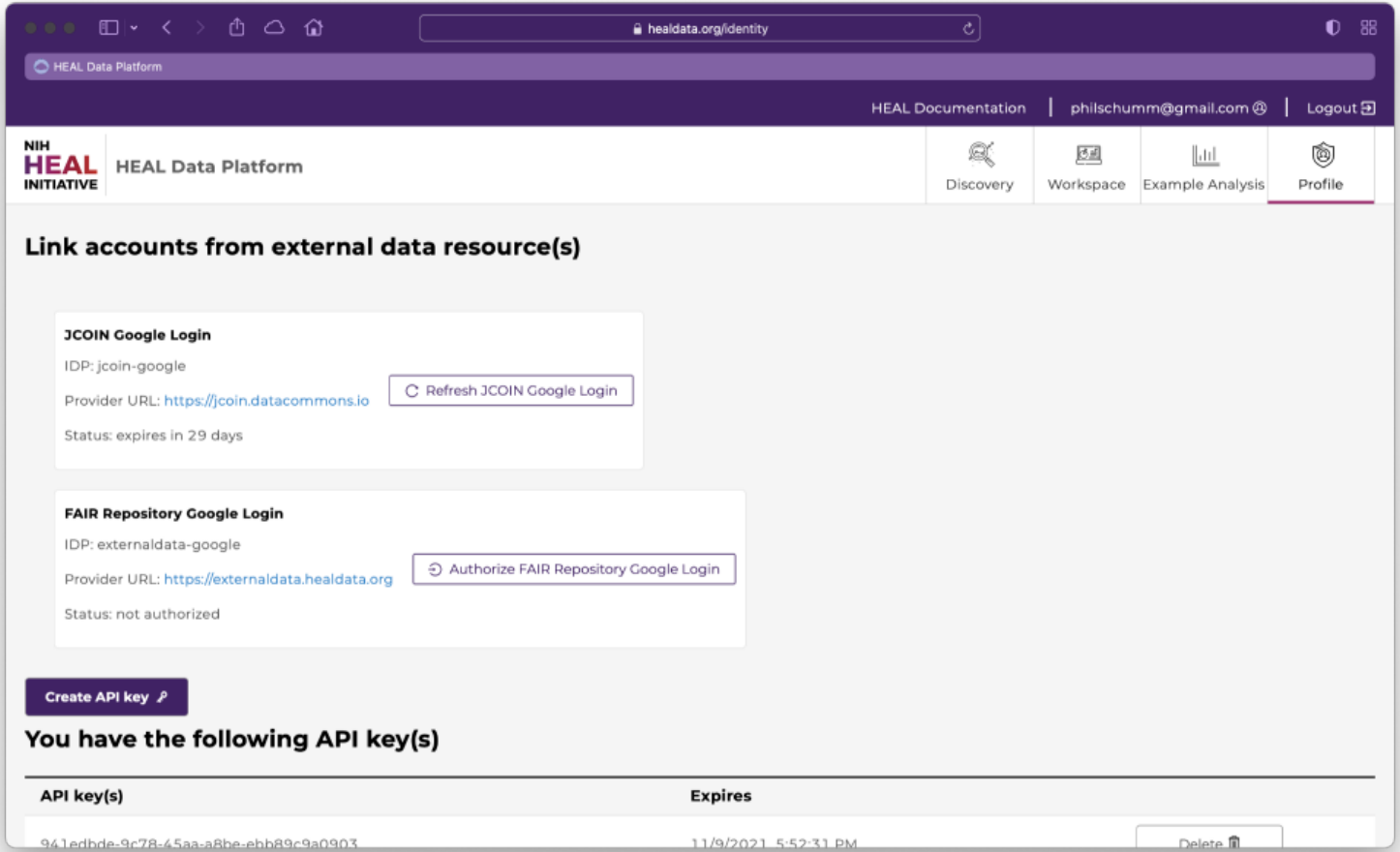
Example Analysis
Profile
Link accounts from external data resource(s)
JCOIN Google Login
IDP: jcoin-google
Provider URL: https://jcoin.datacommons.io
Authorize JCOIN Google Login
Status: not authorized
FAIR Repository Google Login
IDP: externaldata-google
Provider URL: https://externaldata.healdata.org
Authorize FAIR Repository Google Login
Status: not authorized
Create API key
You have the following API key(s)
API key(s)
Expires
941edbde-9c78-45aa-a8be-ebb89c9a0903
11/9/2021, 5:52:31 PM
Delete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Logout
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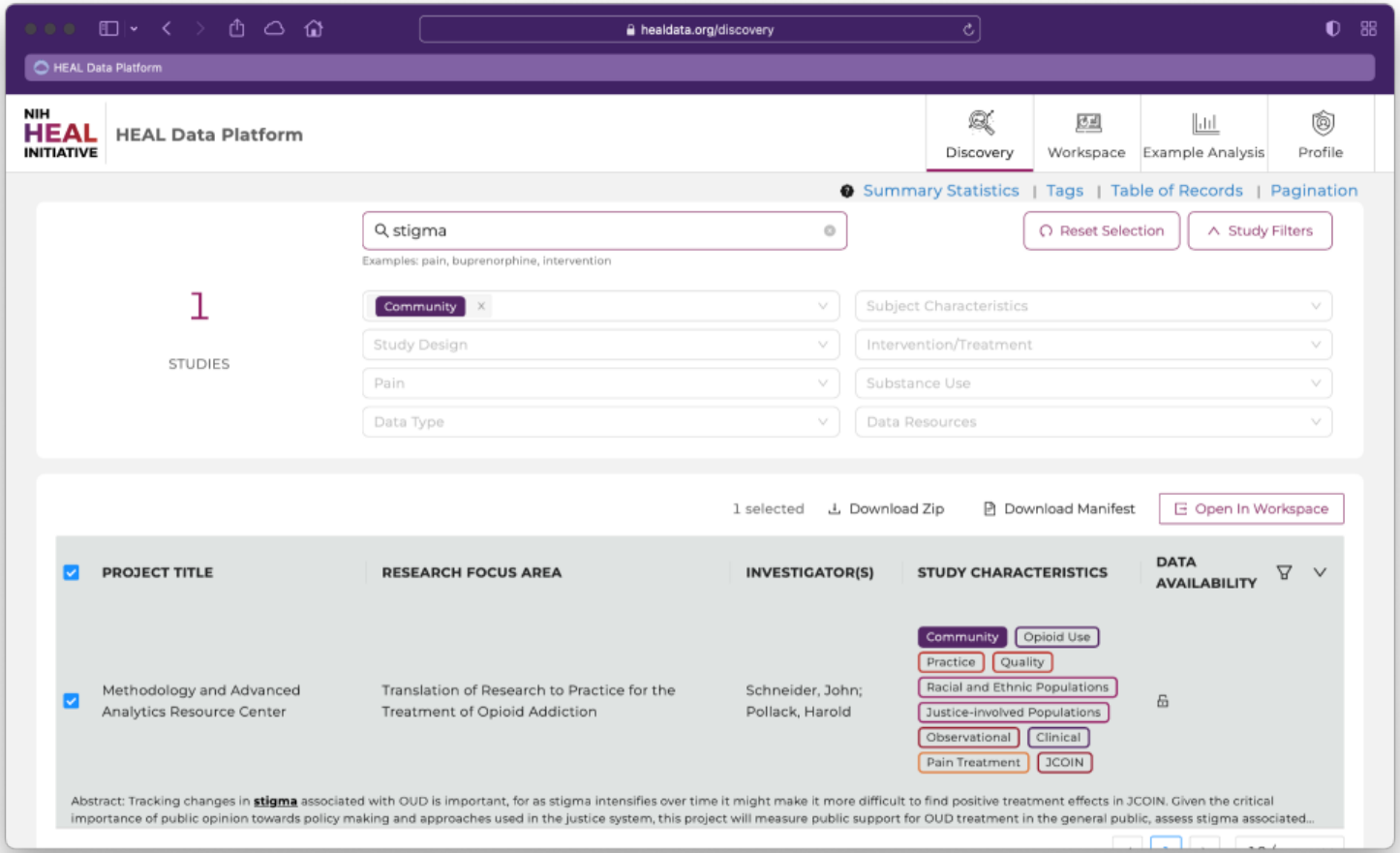
Profile
Link accounts from external data resource(s)
JCOIN Google Login
IDP: jcoin-google
Provider URL: https://jcoin.datacommons.io
Refresh JCOIN Google Login
Status: expires in 29 days
FAIR Repository Google Login
IDP: externaldata-google
Provider URL: https://externaldata.healdata.org
Authorize FAIR Repository Google Login
Status: not authorized
Create API key
You have the following API key(s)
API key(s)
Expires
Delete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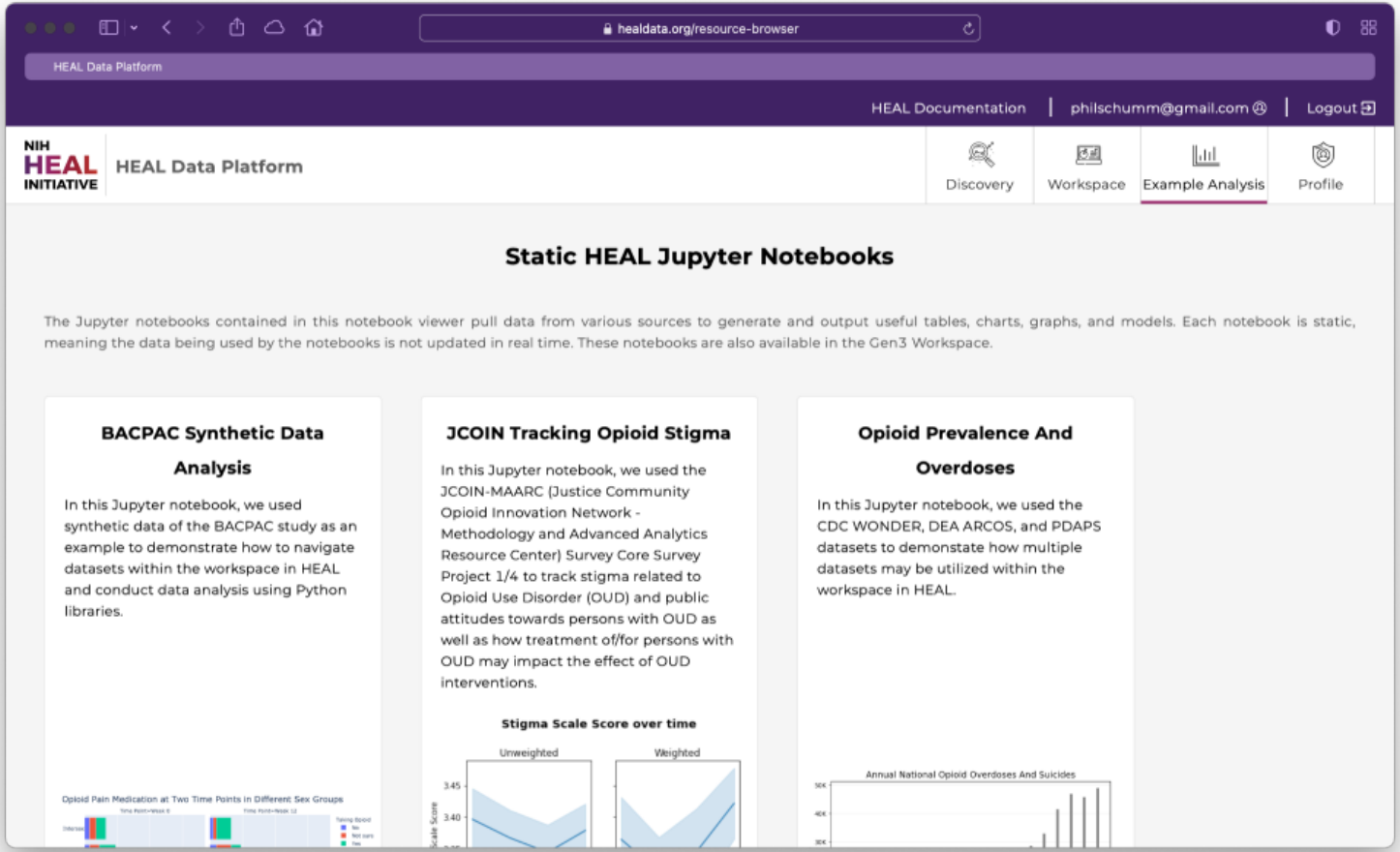
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Example Analysis
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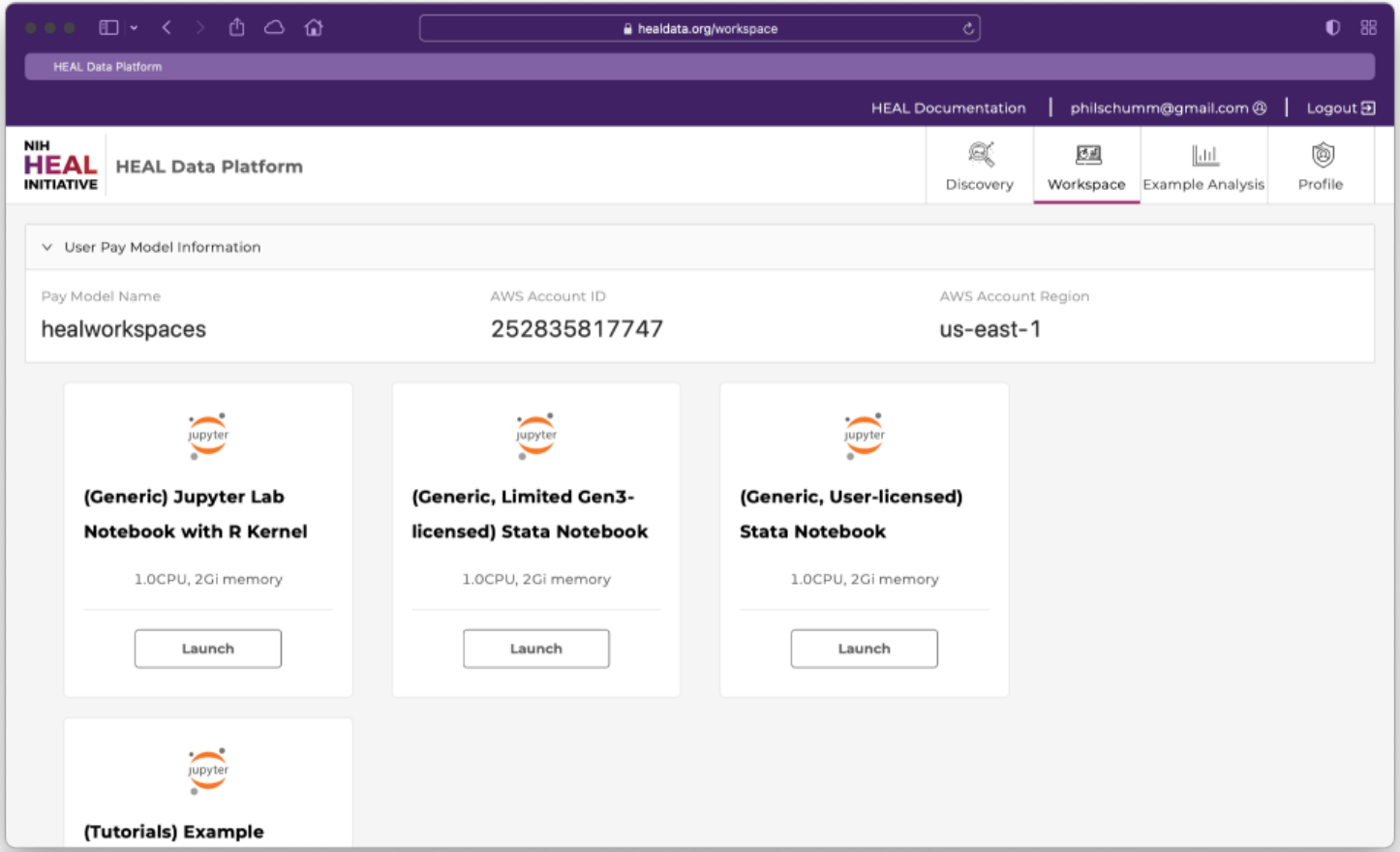
Static HEAL Jupyter Notebooks
The Jupyter notebooks contained in this notebook viewer pull data from various sources to generate and output useful tables, charts, graphs, and models. Each notebook is static, meaning the data being used by the notebooks is not updated in real time. These notebooks are 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.
Opioid Pain Medication at Two Time Points in Different Sex Groups
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.
Stigma Scale Score over time
Unweighted
Weighted
3.45
3.40
Opioid Prevalence And Overdoses
In this Jupyter notebook, we used the CDC WONDER, DEA ARCOS, and PDAPS datasets to demonstate how multiple datasets may be utilized within the workspace in HEAL.
Annual National Opioid Overdoses And Suicides

Workspaces

- Secure use of data leveraging cloud services
- Access to common software and specialized tools
- STRIDES
- Collaboration
- Replicability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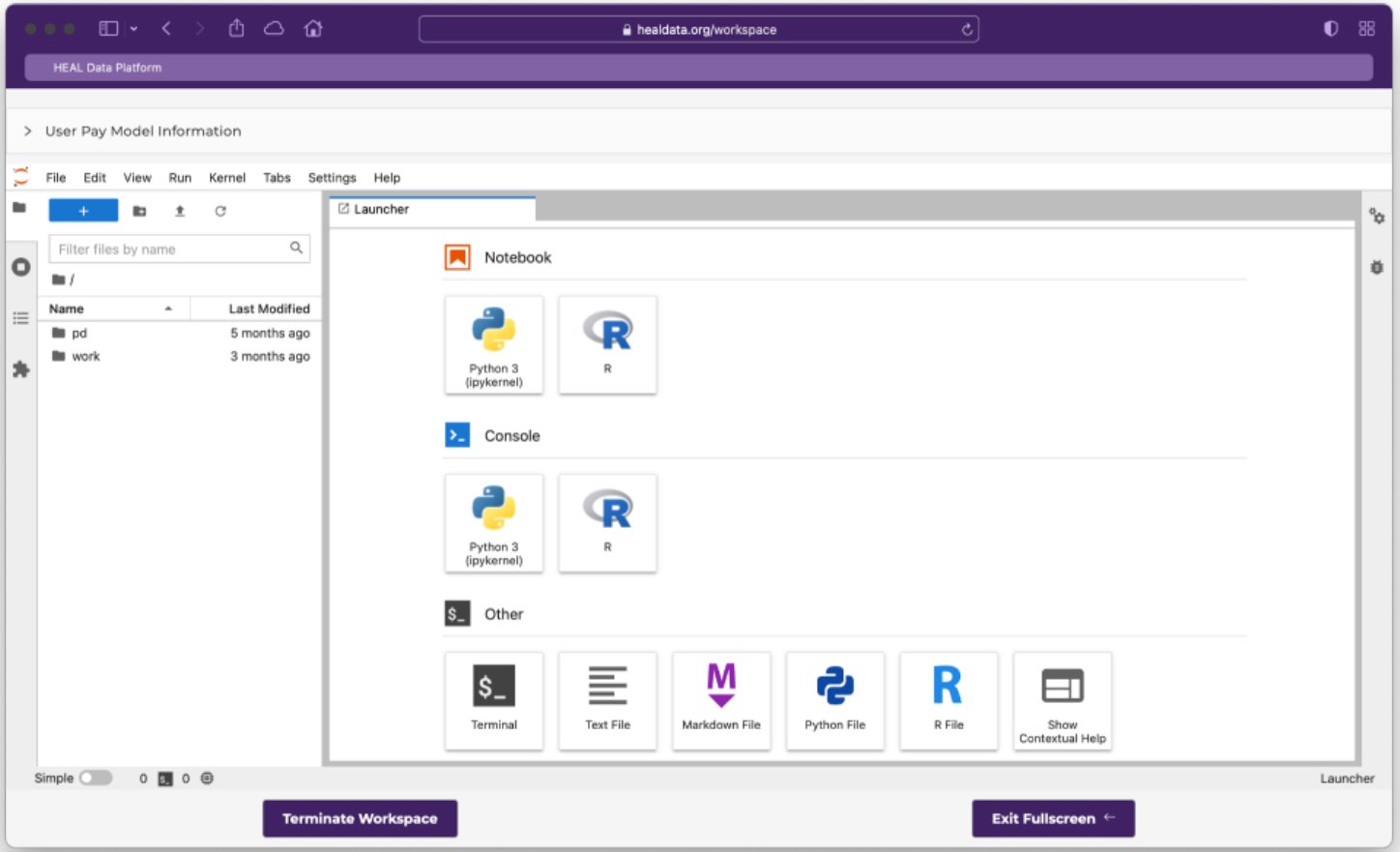
Workspace
Example Analysis
Profile
User Pay Model Information
Pay Model Name
healworkspaces
AWS Account ID
252835817747
AWS Account Region
us-east-1
(Generic) Jupyter Lab Notebook with R Kernel
1.0CPU, 2Gi memory
Launch
(Generic, Limited Gen3-licensed) Stata Notebook
1.0CPU, 2Gi memory
Launch
(Generic, User-licensed) Stata Notebook
1.0CPU, 2Gi memory
Launch
(Tutorials) Example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User Pay Model Information
File Edit View Run Kernel Tabs Settings Help
Filter files by name
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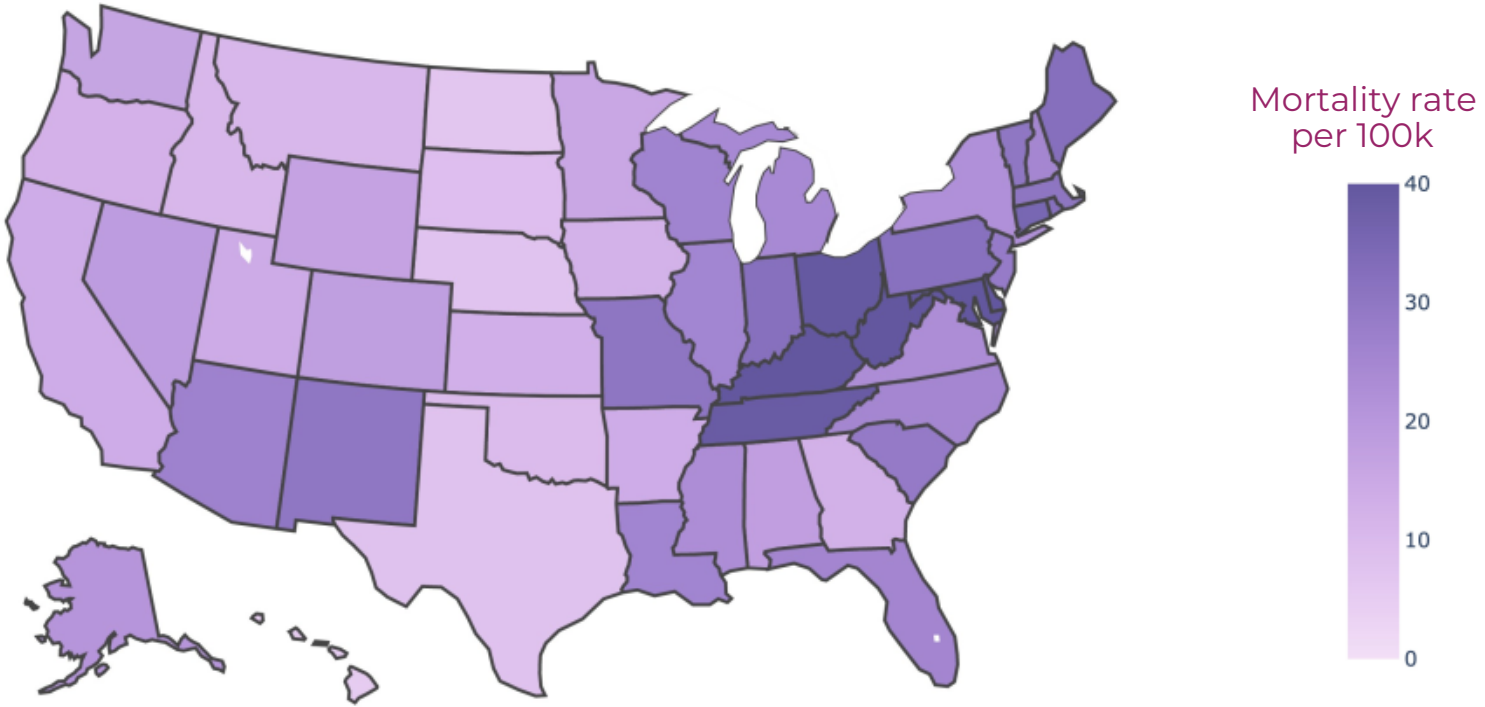
Name
Last Modified
pd
5 months ago
work
3 months ago
Launcher
Notebook
Python 3 (ipykernel)
R
Console
Python 3 (ipykernel)
R
Other
Terminal
Text File
Markdown File
Python File
R File
Show Contextual Help
Simple
0 0
Launcher
Terminate Workspace
Exit Fullscreen

Combining datasets (example)

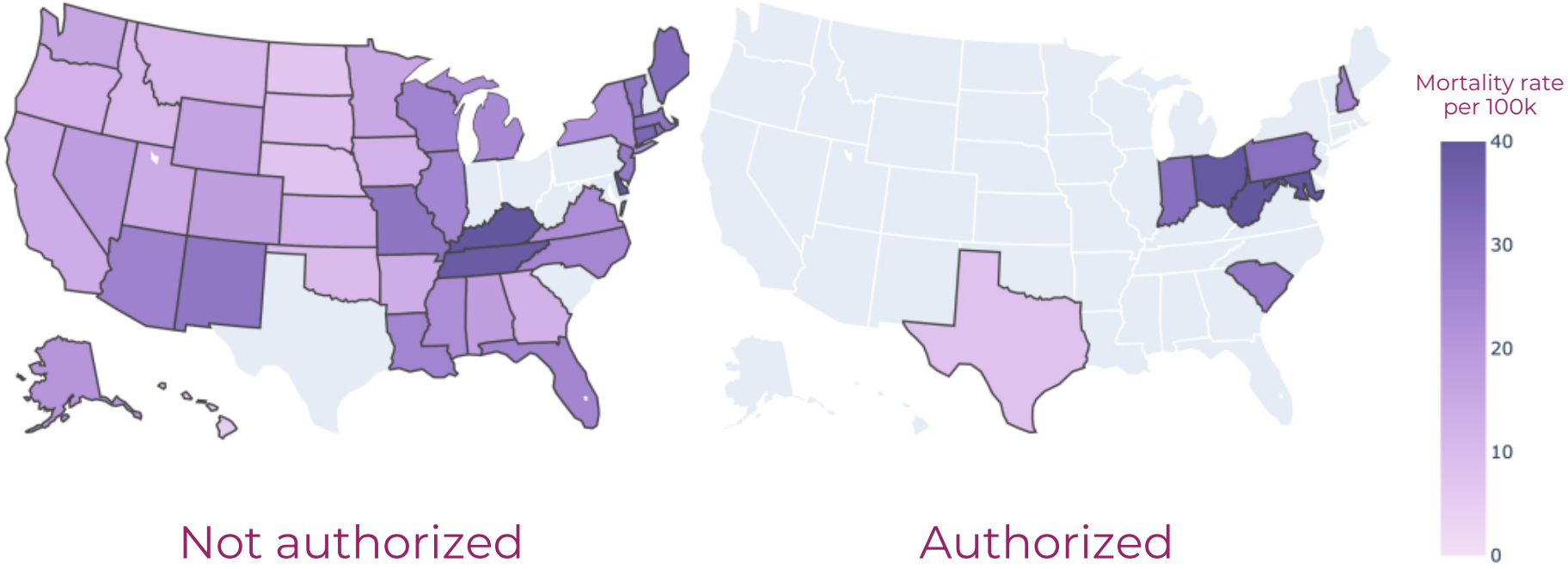
- CDC Wide-ranging Online Data for Epidemiologic Research (CDC WONDER) Mortality Multiple Cause-of-Death Public Use Record

- 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



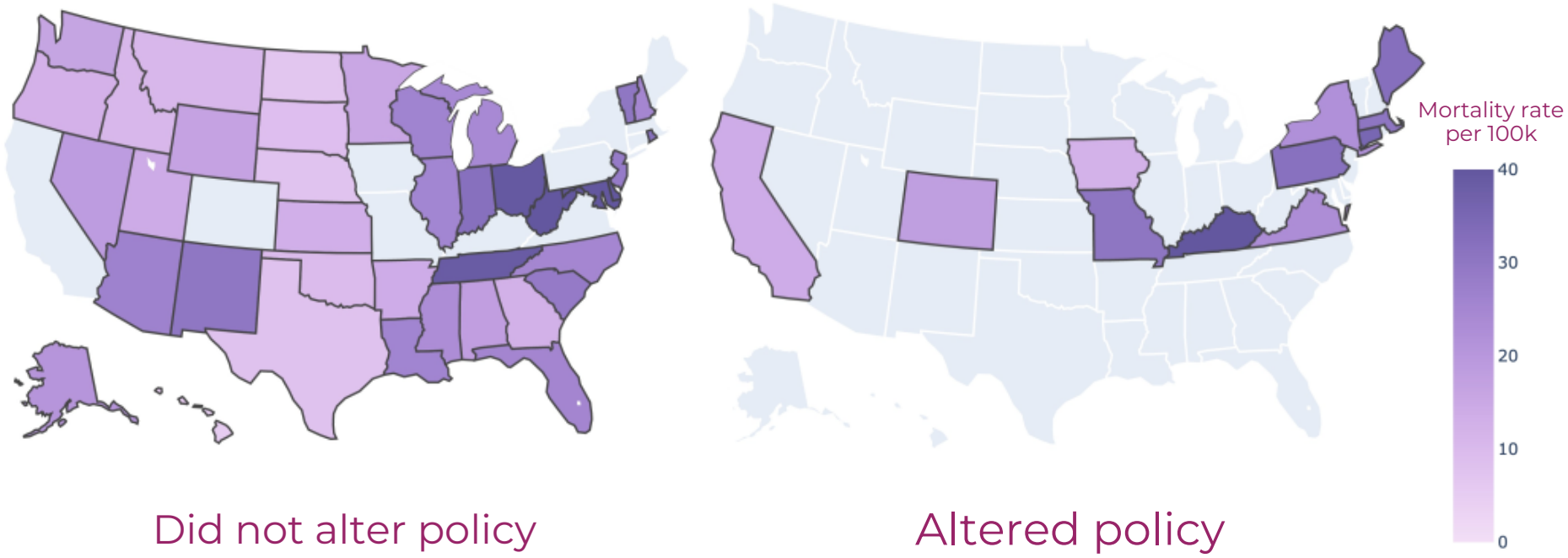
PDAPS: Telehealth for buprenorphine or methadone



Not authorized

Authorized

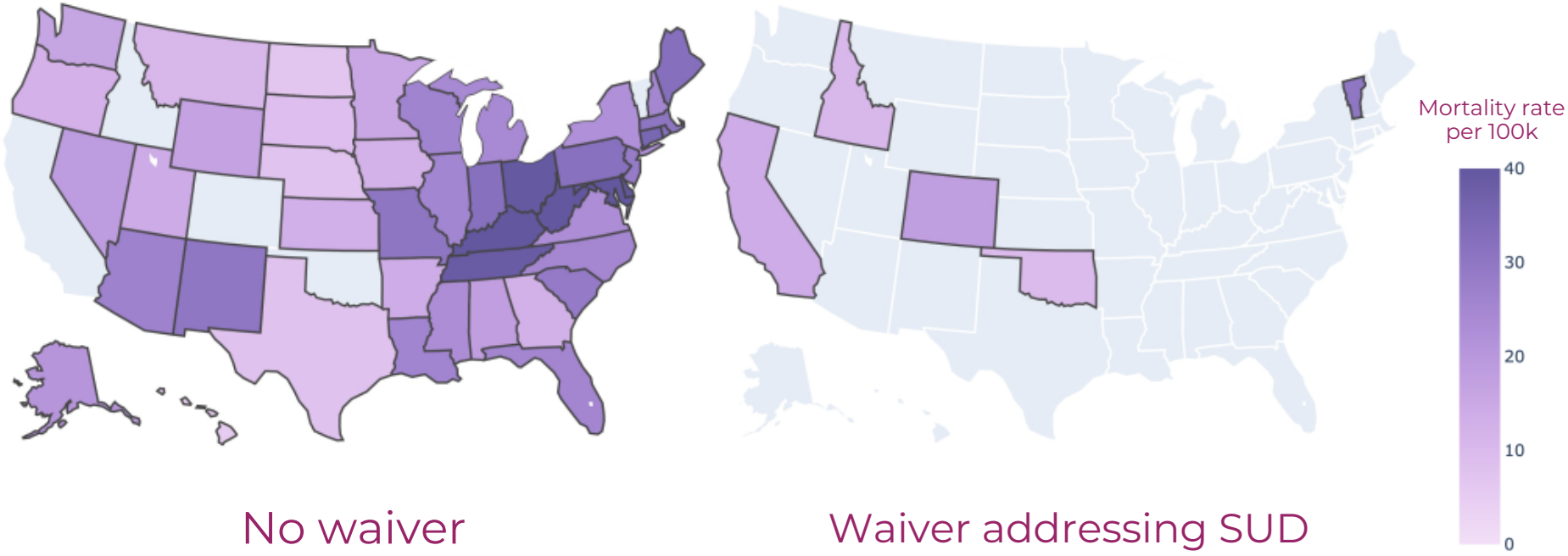
PDAPS: Correctional facilities modified MOUD policy for COVID-19



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