ScHARe Repository
Introduction

November 20, 2024

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ScHARe

Science
collaborative for
Health disparities and
Artificial intelligence bias
Reduction

Outline

15'	ScHARe Overview
5'	Repository Background
5'	Getting Started
15'	Uploading your first Data Set
15'	HANDS ON: Uploading Data
15'	CDE Mapping and Dataviews
15'	HANDS ON: Dataviews for CDE Mapping
5'	Sharing Data
10'	Data Aggregation and Analysis - Overview
15'	Conclusion and Q&A

Experience poll

Please check your level of experience with the following:

	None	Some	Proficient	Expert
Python	☐	☐	☐	☐
R	☐	☐	☐	☐
Cloud computing	☐	☐	☐	☐
Terra	☐	☐	☐	☐
Health disparities research	☐	☐	☐	☐
Health outcomes research	☐	☐	☐	☐
Algorithmic bias mitigation	☐	☐	☐	☐

Interest poll

I am interested in (check all that apply):

- ☐ Learning about Health Disparities and Health Outcomes research to apply my data science skills
- ☐ Conducting my own research using AI/cloud computing and publishing papers
- ☐ Connecting with new collaborators to conduct research using AI/cloud computing and publish papers
- ☐ Learning to use AI tools and cloud computing to gain new skills for research using Big Data
- ☐ Learning cloud computing resources to implement my own cloud
- ☐ Developing bias mitigation and ethical AI strategies
- ☐ Other

ScHARe

What is ScHARe?

BE A PART OF THE FUTURE
OF KNOWLEDGE GENERATION

ScHARe

Science collaborative for Health disparities and Artificial intelligence bias Reduction

Register: nimhd.nih.gov/schare

ScHARe is a cloud-based population science data platform designed to accelerate research in health disparities, health and healthcare delivery outcomes, and artificial intelligence (AI) bias mitigation strategies

ScHARe aims to fill five critical gaps:

- Increase participation of **women & underrepresented populations with health disparities** in data science through data science skills training, cross-discipline mentoring, and multi-career level collaborating on research
- Leverage population science, SDoH, and behavioral Big Data and cloud computing tools to foster a **paradigm shift** in health disparity and healthcare delivery outcomes research
- **Advance AI bias mitigation and ethical inquiry** by developing innovative strategies and securing diverse perspectives
- Provide a **data science cloud computing resource** for community colleges and low resource minority serving institutions and organizations
- Offer a **project data repository** centered on core common data elements for enhanced data interoperability and compliance with NIH Data Management and Sharing Policy

ScHARe

Google Platform Terra Interface

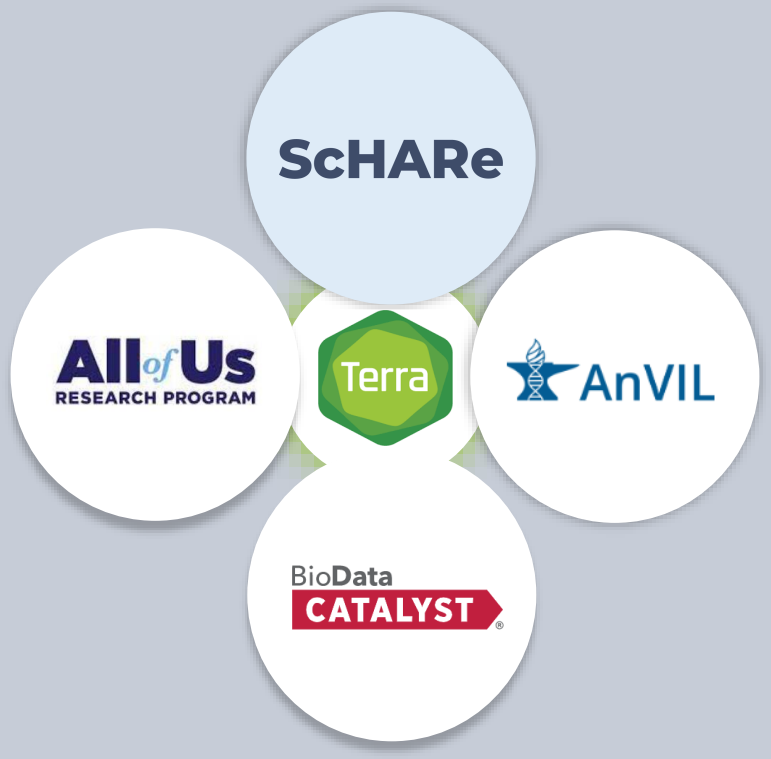
- Secure workspaces
- Data storage
- Computational resources
- Tutorials (how to)
- Copy-and-paste code in Python and R
- Learning Terra on ScHARe prepares you to use other NIH platforms

Terra recommends using **Chrome**

Must have a **Gmail** friendly account

PREPARING FOR AI RESEARCH AND HEALTHCARE USING BIG DATA

Mapping across cloud platforms with Terra interface for collaborative research



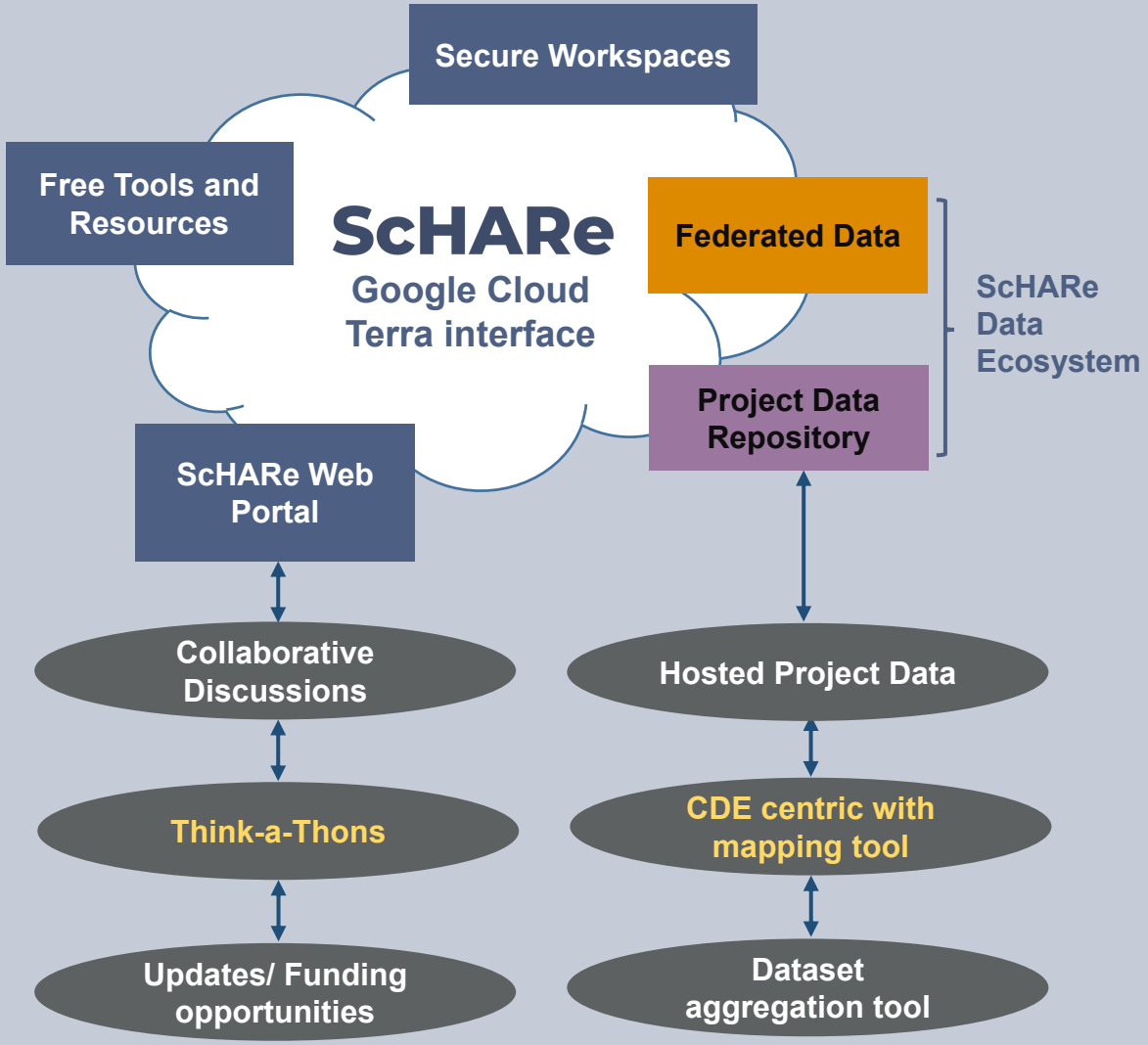
BE A PART OF THE FUTURE OF KNOWLEDGE GENERATION

ScHARe Components

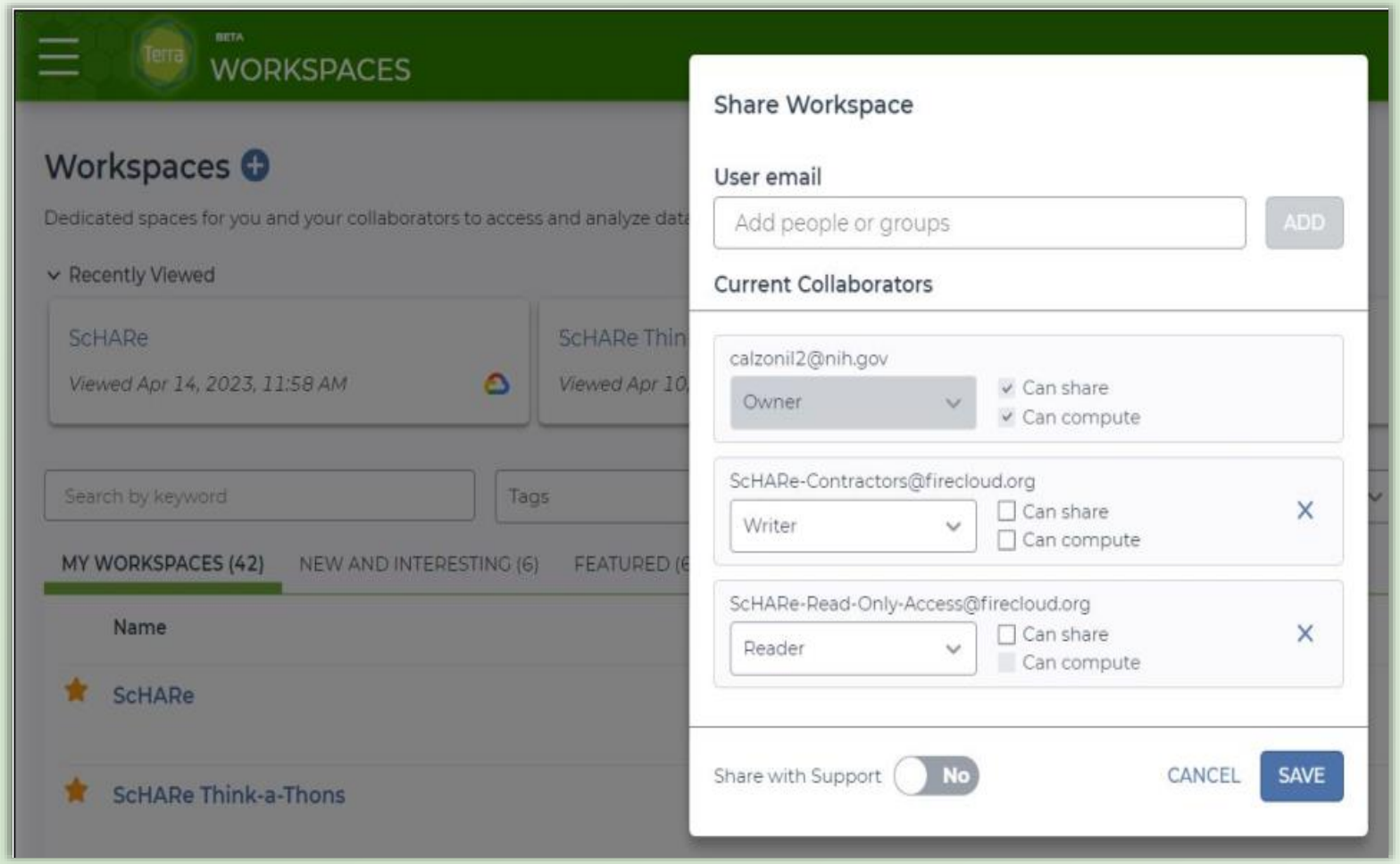
ScHARe co-localizes within the cloud:

1. **Datasets** (including social determinants of health and social science data) relevant to minority health, health disparities, and healthcare outcomes research
2. **CDE-focused data repository** to comply with the required hosting and sharing of data from NIMHD-/NINR-funded programs
3. **User-friendly computational capabilities and secure, collaborative workspaces** for students and all career level researchers
4. **Tools for collaboratively evaluating and mitigating biases** associated with datasets and algorithms utilized to inform healthcare and policy decisions (*upcoming*)

Intramural and Extramural Resource



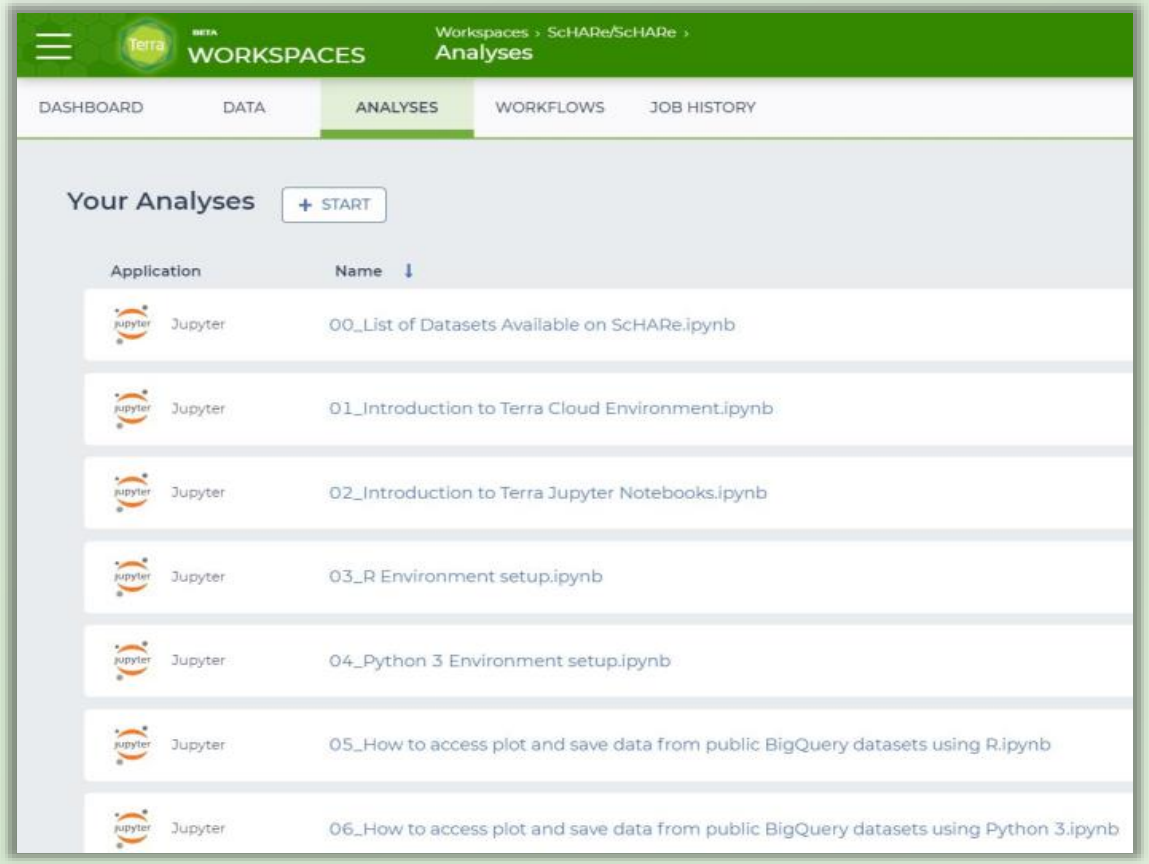
ScHARe Terra interface: secure workspace



- Secure workspace **for self or collaborative research**
- **Assign roles**: review or admin
- **Host own data and code**

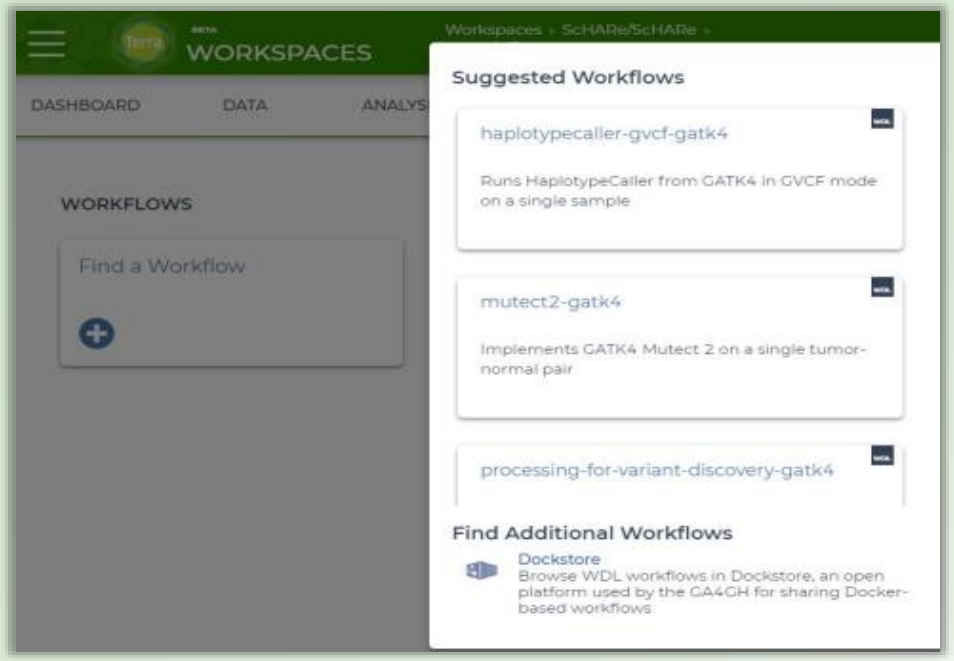
ScHARe Terra interface: analyses

Notebooks for analytics and tutorials



Modular codes

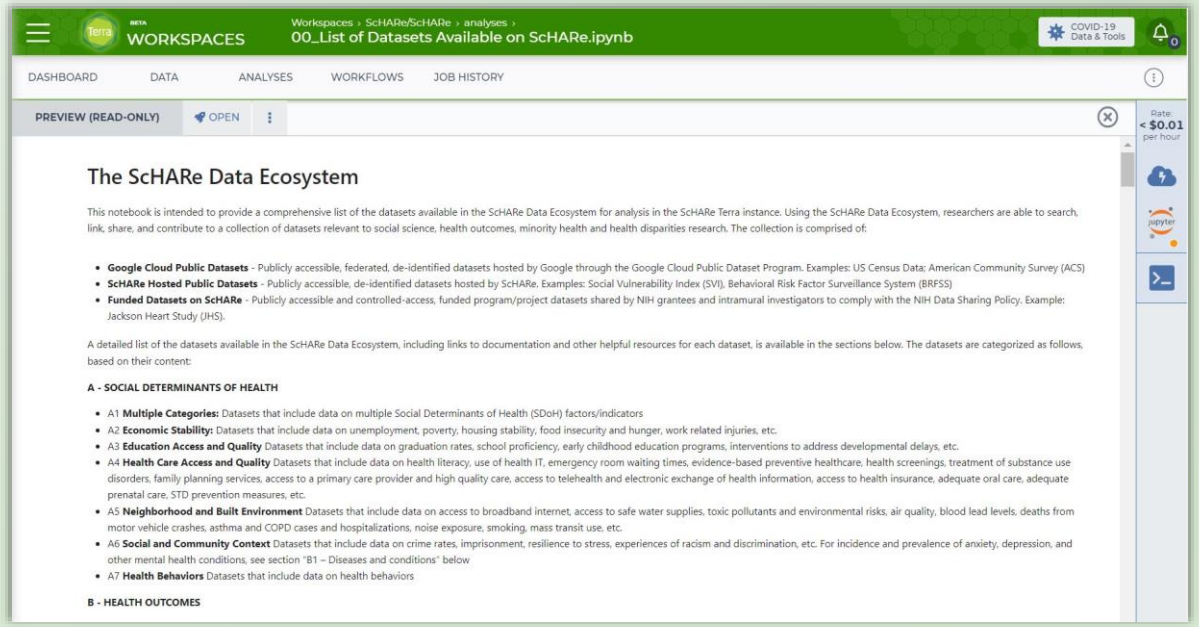
- **Easy-to-use copy and paste analytics**



- Modular codes developed for reuse
- **Adding SAS**

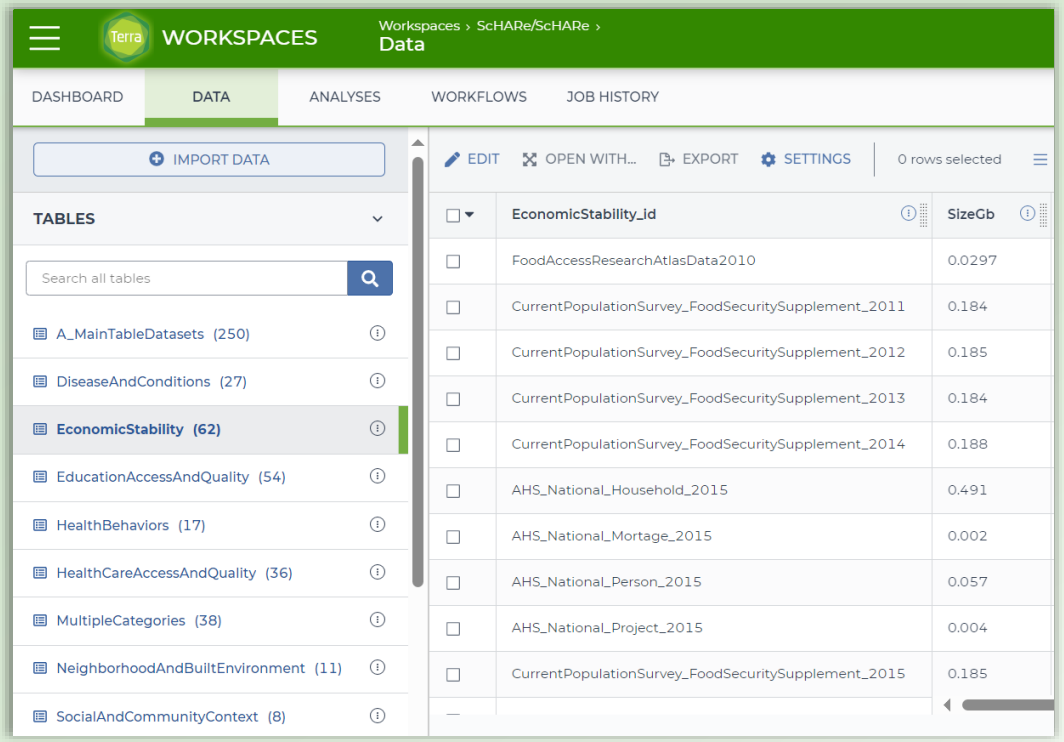
ScHARe Terra interface: access to datasets

What data?



In the **Analyses tab**, the notebook **00_List of Datasets Available on ScHARe** lists all datasets

Where?



In the **Data tab**, data tables help access data

ScHARe Ecosystem structure

Researchers can access, link, analyze, and export **a wealth of SDoH and population science related datasets** within and across platforms relevant to research about health disparities, health care delivery, health outcomes and bias mitigation, including:

280+
FEDERATED PUBLIC DATASETS

Public datasets

Publicly accessible, federated, de-identified datasets hosted by ScHARe or hosted by Google through the Google Cloud Public Dataset Program

ScHARe **e.g.:** *Behavioral Risk Factor Surveillance System (BRFSS)*

Google **e.g.:** *American Community Survey (ACS)*

CDE
FOCUSED REPOSITORY

Funded datasets

Publicly accessible and controlled-access, funded program/project datasets using Common Data Elements shared by NIH grantees and intramural investigators to comply with the NIH Data Sharing Policy

e.g.: *Jackson Heart Study (JHS)*
Extramural Grant Data
Intramural Project Data

Innovative Approach:
CDE Concept Codes
Uniform Resource Identifier (**URI**)

ScHARe Ecosystem

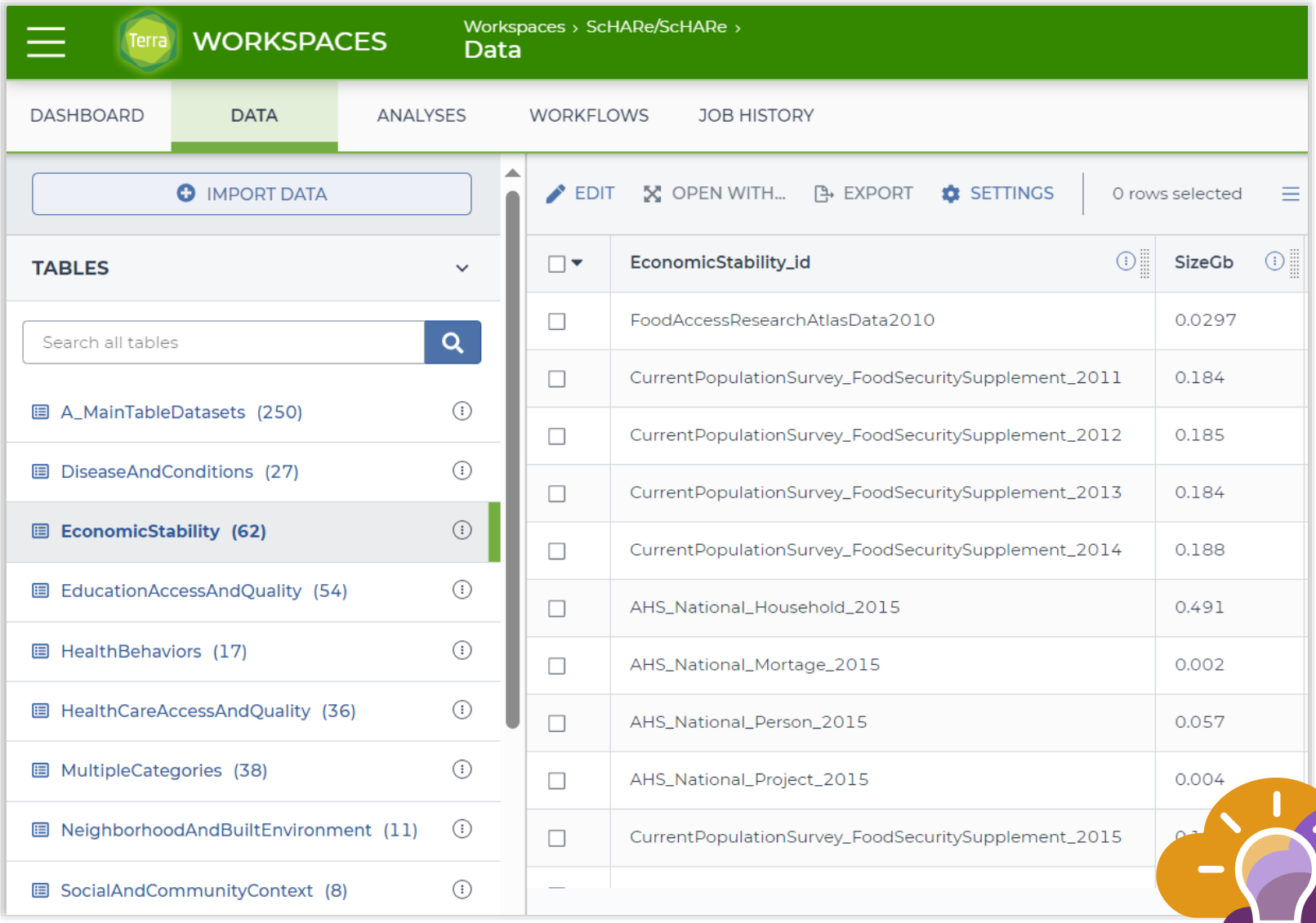
OVER 280 DATA SETS CENTRALIZED

Datasets are categorized by content based on the CDC **Social Determinants of Health categories**:

1. Economic Stability
2. Education Access and Quality
3. Health Care Access and Quality
4. Neighborhood and Built Environment
5. Social and Community Context

with the addition of:

- **Health Behaviors**
- **Diseases and Conditions**



ScHARe Ecosystem: ScHARe hosted datasets

Organized based on the **CDC SDoH categories**, with the addition of *Health Behaviors* and *Diseases and Conditions*:

280+ datasets

- **What are the Social Determinants of Health?**

Social determinants of health (SDoH) are the **nonmedical factors that influence health outcomes**

They are the **conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life**

https://www.cdc.gov/about/priorities/social-determinants-of-health-at-cdc.html?CDC_AAref_Val=https://www.cdc.gov/about/sdoh/index.html

ScHARe Ecosystem: ScHARe hosted datasets

Education access and quality

Data on graduation rates, school proficiency, early childhood education programs, interventions to address developmental delays, etc.

Economic stability

Data on unemployment, poverty, housing stability, food insecurity and hunger, work related injuries, etc.

Health care access and quality

Data on health literacy, use of health IT, preventive healthcare, access to health insurance, etc.

* Health behaviors

Data on health-related practices that can directly affect health outcomes.

Neighborhood and built environment

Data on access to safe water supplies, toxic pollutants and environmental risks, air quality, blood lead levels, noise exposure, smoking, mass transit use, etc.

* Diseases and conditions

Data on incidence and prevalence of specific diseases and health conditions.

Social and community context

Data on crime rates, imprisonment, resilience to stress, experiences of racism and discrimination, etc.

** Not Social Determinants of Health*

ScHARe Ecosystem: Google hosted datasets

Examples of interesting datasets include:

- **American Community Survey** (U.S. Census Bureau)
- **US Census Data** (U.S. Census Bureau)
- **Area Deprivation Index** (BroadStreet)
- **GDP and Income by County** (Bureau of Economic Analysis)
- **US Inflation and Unemployment** (U.S. Bureau of Labor Statistics)
- **Quarterly Census of Employment and Wages** (U.S. Bureau of Labor Statistics)
- **Point-in-Time Homelessness Count** (U.S. Dept. of Housing and Urban Development)
- **Low Income Housing Tax Credit Program** (U.S. Dept. of Housing and Urban Development)
- **US Residential Real Estate Data** (House Canary)
- **Center for Medicare and Medicaid Services - Dual Enrollment** (U.S. Dept. of Health & Human Services)
- **Medicare** (U.S. Dept. of Health & Human Services)
- **Health Professional Shortage Areas** (U.S. Dept. of Health & Human Services)
- **CDC Births Data Summary** (Centers for Disease Control)
- **COVID-19 Data Repository by CSSE at JHU** (Johns Hopkins University)
- **COVID-19 Mobility Impact** (Geotab)
- **COVID-19 Open Data** (Google BigQuery Public Datasets Program)
- **COVID-19 Vaccination Access** (Google BigQuery Public Datasets Program)

How to access Google hosted datasets

Big Query

The Google public datasets are **available for access on Terra using BigQuery**

- BigQuery is the Google Cloud storage solution for structured data
- It is easy to use, works with large amounts of data and offers fast data retrieval and analysis
- Our **instructional notebooks in the Analyses tab** provide code and instructions on using Big Query to access Google datasets

Jupyter 06_How to access plot and save data from public BigQuery datasets using Python 3.ipynb

The following Python code will read a BigQuery table into a Pandas dataframe.

From https://cloud.google.com/community/tutorials/bigquery-ibis

Ibis is a Python library for doing data analysis. It offers a Pandas-like environment for executing data analysis composable, and familiar replacement for SQL.

In [9]:
```
# Connect to the dataset
conn = ibis.bigquery.connect(dataset_id='bigquery-public-data.broadstreet_adi')
```

In [10]:
```
# Read table
ADI_table_2 = conn.table('area_deprivation_index_by_census_block_group')
ADI_table_2
```

Out[10]:
```
BigQueryTable[table]
  name: bigquery-public-data.broadstreet_adi.area_deprivation_index_by_census_block_group
  schema:
    geo_id : string
    state_fips_code : string
    county_fips_code : string
    block_group_fips_code : string
    description : string
    county_name : string
    state_name : string
    state : string
    year : int64
    area_deprivation_index_percent : float64
```

ScHARe

The ScHARe Data Ecosystem

This document is intended to provide a comprehensive list of the datasets available in the ScHARe Data Ecosystem for analysis in the ScHARe Terra instance. Using the ScHARe Data Ecosystem, researchers are able to search, link, share, and contribute to a collection of datasets relevant to social science, health outcomes, minority health and health disparities research.

The collection is comprised of:

- **Google-hosted Public Datasets** - Publicly accessible, federated, de-identified datasets hosted by Google through the Google Cloud Public Dataset Program. Examples: US Census Data; American Community Survey (ACS)
- **ScHARe-hosted Public Datasets** - Publicly accessible, de-identified datasets hosted by ScHARe. Examples: Social Vulnerability Index (SVI), Behavioral Risk Factor Surveillance System (BRFSS)
- **ScHARe-hosted Project Datasets** - Publicly accessible and controlled-access, funded program/project datasets shared by NIH grantees and intramural investigators to comply with the

Jackson Heart Study (JHS)

ScHARe
Datasets PDF list

Scan me

bit.ly/ScHARe-datasets

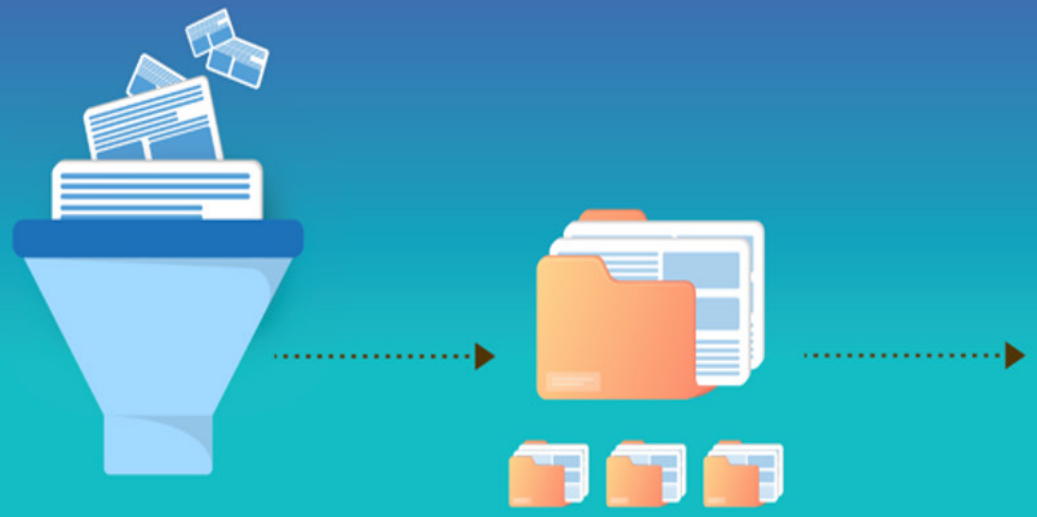
CDE benefits:

- Faster start-up for project
- Better data aggregation across projects
- Shared meaning
- Concept-focused to allow questions/answers variations
- Coding enables an URI approach for better data interoperability

A **Common Data Element** (CDE) is a standardized, precisely defined question, paired with a set of allowable responses, used systematically across different sites, studies, or clinical trials to ensure consistent data collection

Because Researchers use CDEs...

they can more quickly share data and get results faster, which ultimately can help make a **meaningful difference to our nation's health.**



For more information about how CDEs accelerate research discoveries, visit: cde.nlm.nih.gov/resources

ScHARe Core CDEs

PhenX Toolkit

NIH Endorsed

- Age
- Birthplace
- Zip Code
- Race and Ethnicity
- Sex
- Gender
- Sexual Orientation
- Marital Status
- Education
- Annual Household Income
- Household Size

- English Proficiency
- Disabilities
- Health Insurance
- Employment Status
- Usual Place of Health Care
- Financial Security / Social Needs
- Self-Reported Health
- Health Conditions (and Associated Medications/Treatments)

- **NIMHD Framework***
- **Health Disparity Outcomes***

* Project Level CDEs

ScHARe has developed **Common Data Elements** to ensure consistent data collection across studies, facilitate interoperability, and link data from different sources

NIH CDE Repository:
cde.nlm.nih.gov/home
PhenX Toolkit:
www.nimhd.nih.gov/resources/phenx/

bit.ly/NIMHD-RF

NIMHD Research Framework

Domains of Influence (Over the Lifecourse)	Levels of Influence*			
	Individual	**Interpersonal**	**Community**	**Societal**
Biological	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes	**Individual Health**	**Family/ Organizational Health**	**Community Health**	**Population Health**

Project Level CCDEs – Framework

What NIMHD Research framework levels and domains of influence is your study targeting? (Select all that apply)

Levels of Influence

- ☐ Individual
- ☐ Interpersonal
- ☐ Community
- ☐ Societal

Domains of Influence

- ☐ Biological
- ☐ Behavioral
- ☐ Physical/Built Environments
- ☐ Sociocultural Environment
- ☐ Health Care Systems and Clinical Care

NIMHD Research Framework. https://www.nimhd.nih.gov/about/overview/research-framework/nimhd-framework.html

NIMHD's Mission: Improve Minority Health

Minority Health: Distinctive health characteristics and attributes of racial and/or ethnic minority populations who are socially disadvantaged due in part to being subject to racist or discriminatory acts and are underserved in health care.

Minority Health Research

The scientific investigation of singular and combinations of attributes, characteristics, behaviors, biology, and societal and environmental factors that influence the health of minority racial and/or ethnic population(s), including within-group or ethnic sub-populations, with the goals of improving health and preventing disease.

Minority Health Populations

The OMB Directive 15 defines racial and ethnic minority populations as:

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino American
- Middle Eastern or North African
- Native Hawaiian or Pacific Islander

NIMHD's Mission: Reduce Health Disparities

Health Disparity:
A health disparity is a health difference that adversely affects disadvantaged populations in comparison to a reference population, based on one or more health outcomes.

All populations with health disparities are socially disadvantaged due in part to being subject to racist or discriminatory acts and are underserved in health care.

Health Disparity Research

A multi-disciplinary field of study devoted to:

- Gaining greater scientific knowledge about the influence of health determinants.
- Understanding the role of mechanisms.
- Determining how this knowledge is translated into interventions to reduce or eliminate adverse health outcomes.

Populations with Health Disparities

Populations that experience health disparities include:

- Racial and ethnic minority groups
- People with lower socioeconomic status (SES)
- Underserved rural communities
- Sexual and gender minority (SGM) groups
- People with disabilities

Health Disparity Outcomes

Unfair disadvantages that people face in different aspects of life, like education, income, or opportunities **can lead to health disparities**

Some groups of people may experience poorer health outcomes than others as a result

Health Disparity Outcomes

The health outcomes are categorized as:

- Higher incidence and/or prevalence of disease, including earlier onset or more aggressive progression of disease.
- Premature or excessive mortality from specific health conditions.
- Greater global burden of disease, such as Disability Adjusted Life Years (DALY), as measured by population health metrics.
- Poorer health behaviors and clinical outcomes related to the aforementioned.
- Worse outcomes on validated self-reported measures that reflect daily functioning or symptoms from specific conditions.

Project Level CCDEs – Research Area Focus

Which of the following content areas of research is this study addressing, if any? Select all that apply.

- ☐ Minority health
- ☐ Health Disparity (select the focus area)
  - ☐ Higher incidence and/or prevalence of disease, including earlier onset or more aggressive progression of disease
  - ☐ Premature or excessive mortality from specific health conditions
  - ☐ Greater global burden of disease, such as Disability Adjusted Life Years (DALY), as measured by population health metrics
  - ☐ Poorer health behaviors and clinical outcomes related to the aforementioned
  - ☐ Worse outcomes on validated self-reported measures that reflect daily functioning or symptoms from specific conditions
- ☐ Other Health Outcomes / Health Delivery or care

Duran DG, Pérez-Stable EJ. Novel Approaches to Advance Minority Health and Health Disparities Research. Am J Public Health. 2019 Jan; 109(S1):S8-S10. doi: 10.2105/AJPH.2018.304931. PMID: 30699017; PMCID: PMC6356124. *ADAPTED with Other health outcomes delivery/care*

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Introduction

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ScHARe

Research Think-a-Thons

- Novice **training webinars** for data science, cloud computing and research using Big Data
- **Target:** underrepresented populations, women, racial/ethnic and sexual gender minorities, rural and poor populations

Generational career & discipline exchange

Think-a-Thons

3rd Wednesday of every month 2 pm

Goals:

- Upskill underrepresented populations in data science and cloud computing
- Foster a research paradigm shift to use Big Data in health disparities/health outcomes research
- Promote use of Dark Data

1. TUTORIAL AND TARGETED THINK-A-THONS

Launched April 2024

- Monthly sessions (2 1/2 hours)
- Instructional/interactive
- Designed for new/experienced users
- Networking
- Mentoring and coaching
- Topics include:
  - Data Science 101
  - Terra
  - Social Determinants of Health analytics
  - Common Data Elements
  - AI readiness
  - Ethical and transparent AI
  - Bias mitigation

2. RESEARCH THINK-A-THONS

- Multi-career (students to senior investigators)
- Multi-discipline (data scientists and researchers)
- Featured datasets with guest experts leads
- Guest experts in topic areas, analytics, data sources etc. to provide guidance
- Generate research idea - decide design, datasets and analytics
- Learn Ethical AI
- Publications

Register:

bit.ly/think-a-thons

Think-a-Thon tutorials

bit.ly/think-a-thons

SPECIAL EVENTS

- ScHARe for **Educators** (Community Colleges and low-resource MSIs)
- ScHARe for **American Indian/ Alaska Native Researchers**
- ScHARe for **Coders and Programmers** to conduct research

Think-a-thon Archive

February	**Artificial Intelligence and Cloud Computing 101**

Recent Think-a-thons

October	**Preparing for AI 1: Common Data Elements and Data Aggregation**
November	**Preparing for AI 2: An Introduction to FAIR Data and AI-ready Datasets**
January	**Preparing for AI 3: Computational Data Science Strategies 101**
February/March	**Preparing for AI 4: Overview Prep for AI Summary with Transparency, Privacy, Ethics**
April	**Research Teams – SDoH and Health Disparities**
May	**Be a Part of the Future of Knowledge Generation 1: AI/Cloud Computing Basics and CDEs**
July	**Be a Part of the Future of Knowledge Generation 2: AI-Ready Datasets and Computations**
August	**An Introduction to Python for Data Science**
September	**Data Management and Analysis in Python**
October	**ScHARe Data Repository**

Experience conducting ethical AI

Transparency

Public perception and understanding of how AI works

- **Technical documentation for duplication/re-use**
- **Tools:**
  - Data dictionary
  - Health sheet (Data sheet)
  - Model cards (capabilities and purpose of algorithms are openly and clearly communicated to relevant stakeholders)

Fairness

Findable: *providing metadata, documentation, and clear identifiers*
Accessible: *wide audience*
Interoperable: *standardized formats and APIs enable seamless integration*
Reusable: *clear documentation, licensing, reduce redundancy*

- Metadata and data should be easy to find for both humans and computers
- Ensure that data represents relevant populations

Think-a-Thons training/mentoring pipeline

NLM
OIC Experts
Fellows

+

Think-a-Thons

- ✓ Instructional
- ✓ Research

+

AIM-AHEAD

+

AnVil | **HEAL**
N3C | **All of US**
BioData Catalyst

Using AI experts

to train and mentor novice AI users

to upskill and mentor diverse perspectives in AI

to increase diverse perspectives in biomedical research

Goal: "Upskilling"

- ✓ Data science specialists into health disparities and health outcomes research
- ✓ Health disparities/outcomes researchers into using big data and cloud computing

Target Audience:

- ✓ Underrepresented populations (women, race/ethnic) users not trained in data science
- ✓ Data scientists with no or little research experience
- ✓ Resource and tool for Community Colleges and low-resource MSIs and organizations

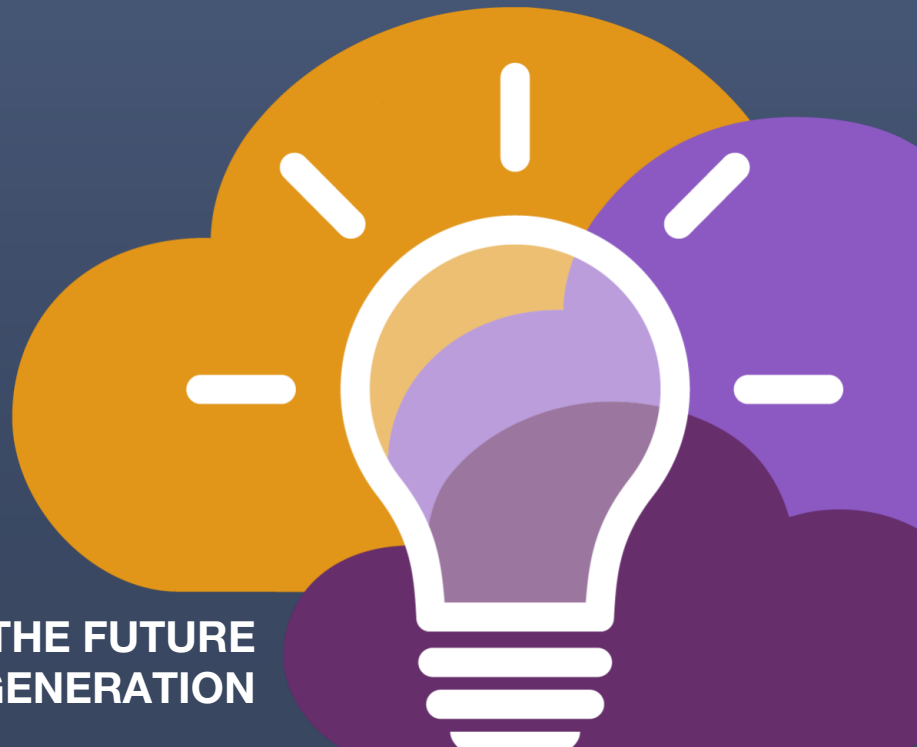
Slido Poll

Which statement is most true for Common Data Elements:

a) Questions that are forced upon investigators to use
b) Questions that are asked the same way for everyone involved in a study
c) Questions that are universally semantically defined and can be used similarly by all
d) Questions that require a series of questions and a set of responses only relevant to the study

ScHARe

Getting Started on Terra



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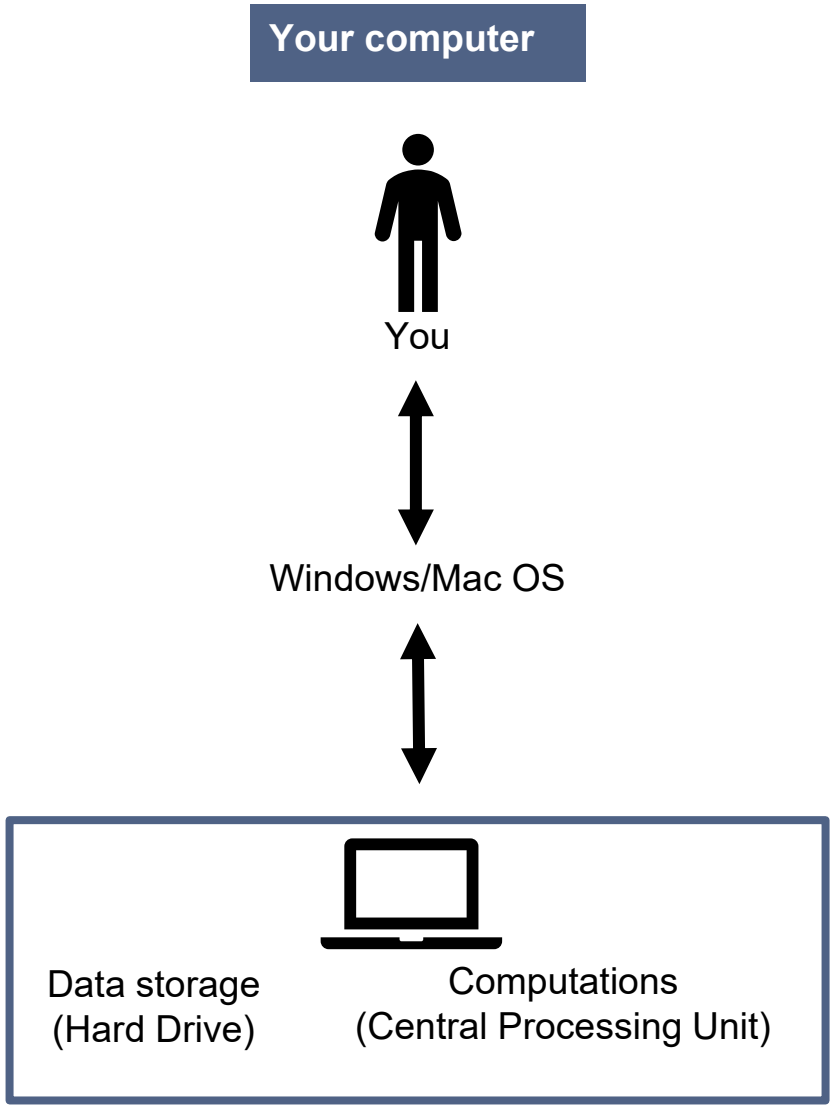
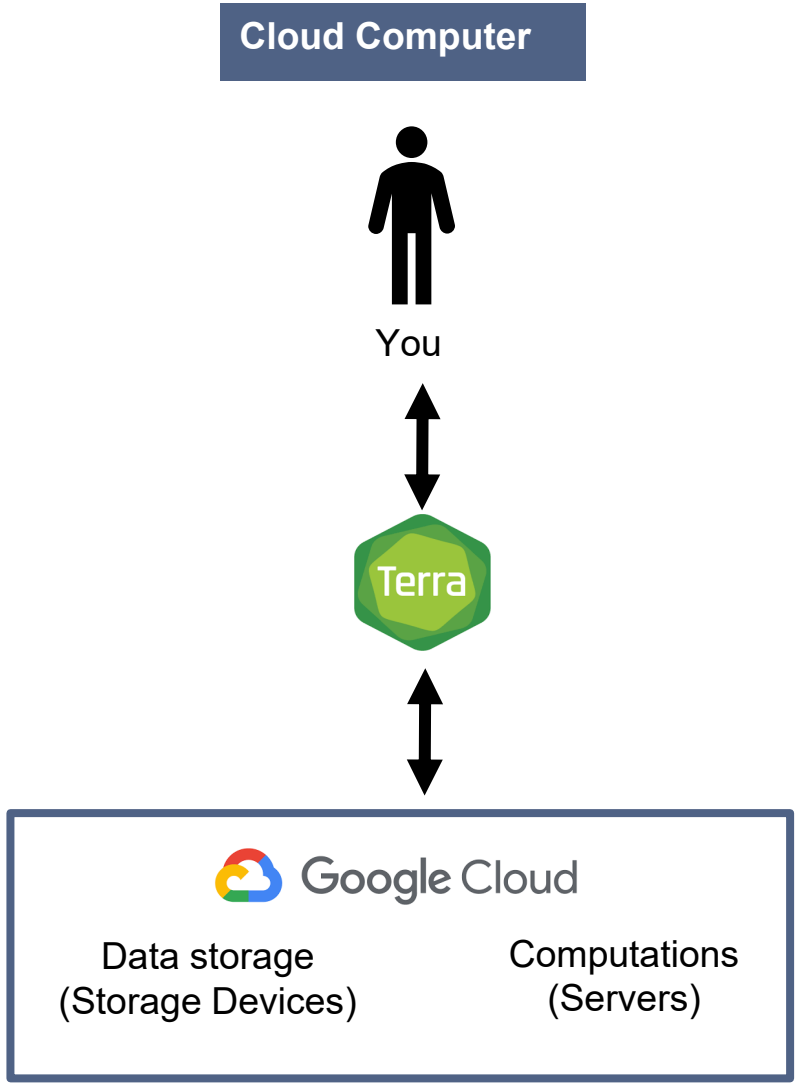
OF KNOWLEDGE GENERATION

ScHARe provides an easy portal to cloud computing





Today’s mission

Getting Set Up on Terra	A tour of the ScHARe Workspace	Your first steps
Register for ScHARe		
Create a Terra Account		
Link a billing account		

Today’s mission

Getting Set Up on Terra

Register for ScHARe

ScHARe Registration Form

Create a Terra Account

Link a billing account

A tour of the ScHARe Workspace

Your first steps

Today’s mission

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Terra

Link a billing account

Google Cloud

A tour of the ScHARe Workspace

Your first steps

Slido Poll

Which of the following do you NOT need to do before running your own data analysis on Terra?

A. Link a Google Cloud Billing account to your Terra account
B. Use an .edu email account to create a Terra account
C. Use a Google account to register for SCHARE
D. Create a Terra account

Today’s mission

Getting Set Up on Terra

Register for ScHARe

ScHARe Registration Form

Create a Terra Account

Terra

Link a billing account

Google Cloud

A tour of the ScHARe Workspace

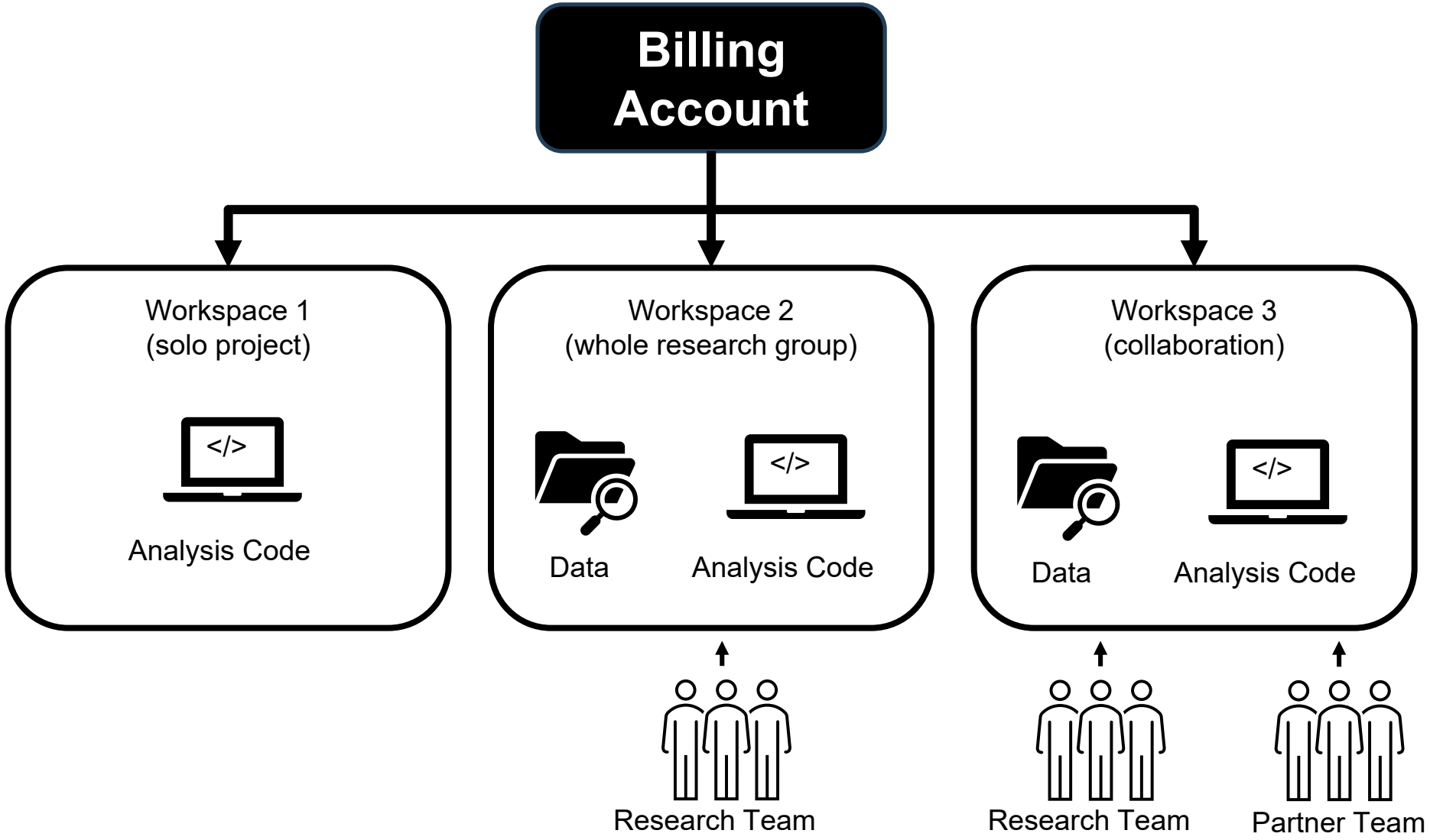
Terra Terminology

ScHARe Workspace: Data Tab

ScHARe Workspace: Analyses Tab

Your first steps

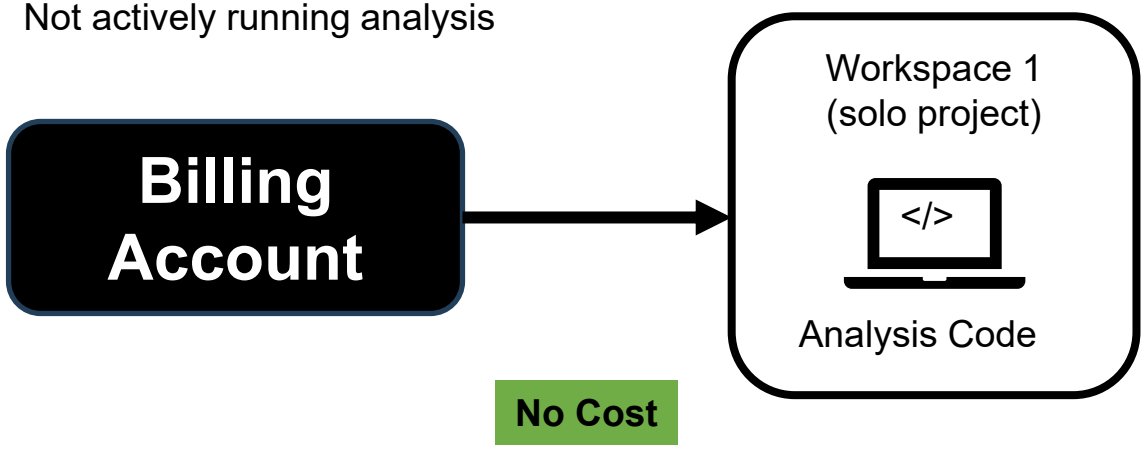
An intro to Terra Terminology



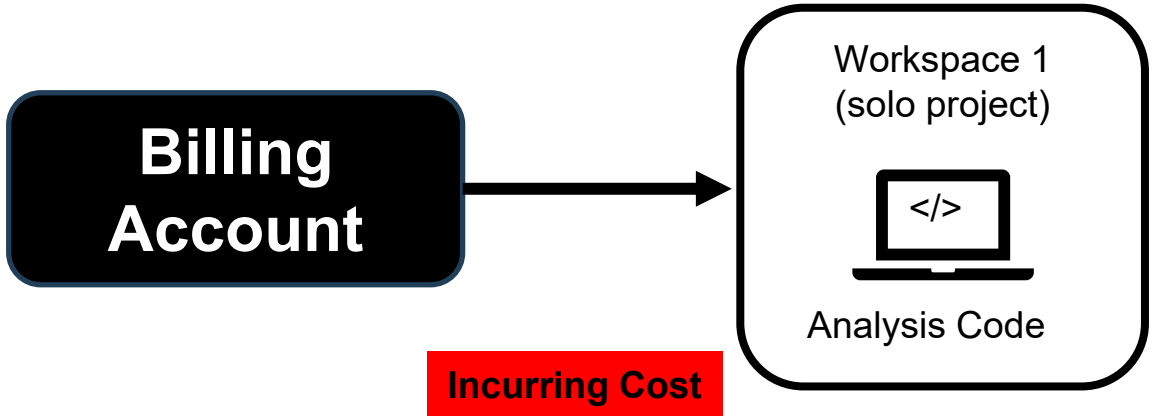
What costs money on Terra

Scenario 1: Analysis Code Only (pulling in data live)

Not actively running analysis

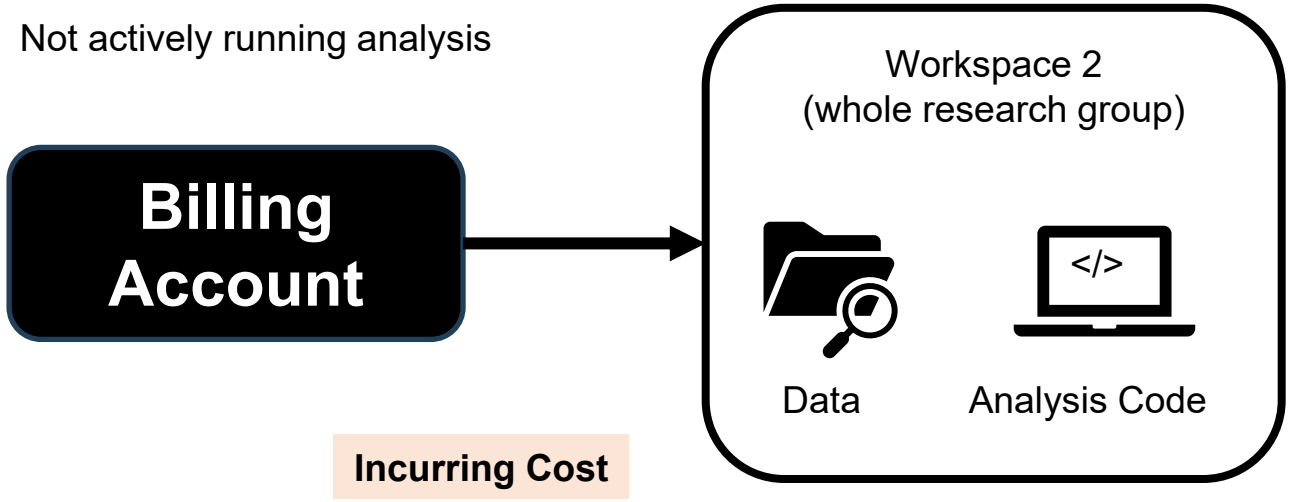


Actively running analysis

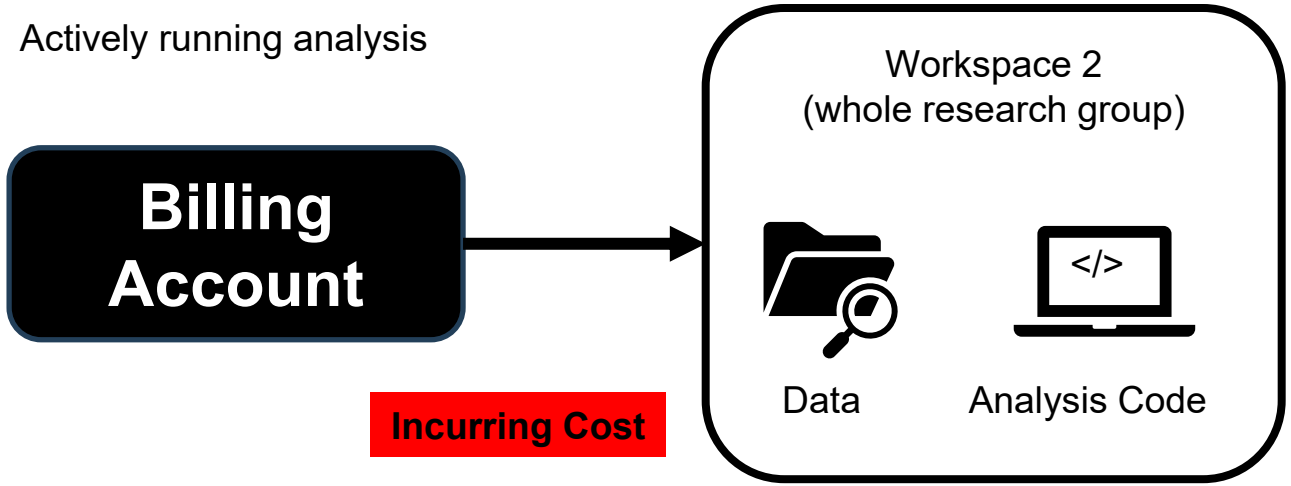


Scenario 2: Analysis Code and Data (storing data in the workspace)

Not actively running analysis



Actively running analysis



Today’s mission

Getting Set Up on Terra

Register for ScHARe

ScHARe Registration Form

Create a Terra Account

Terra

Link a billing account

Google Cloud

A tour of the ScHARe Workspace

Terra Terminology

Terra WORKSPACES

ScHARe Workspace: Data Tab

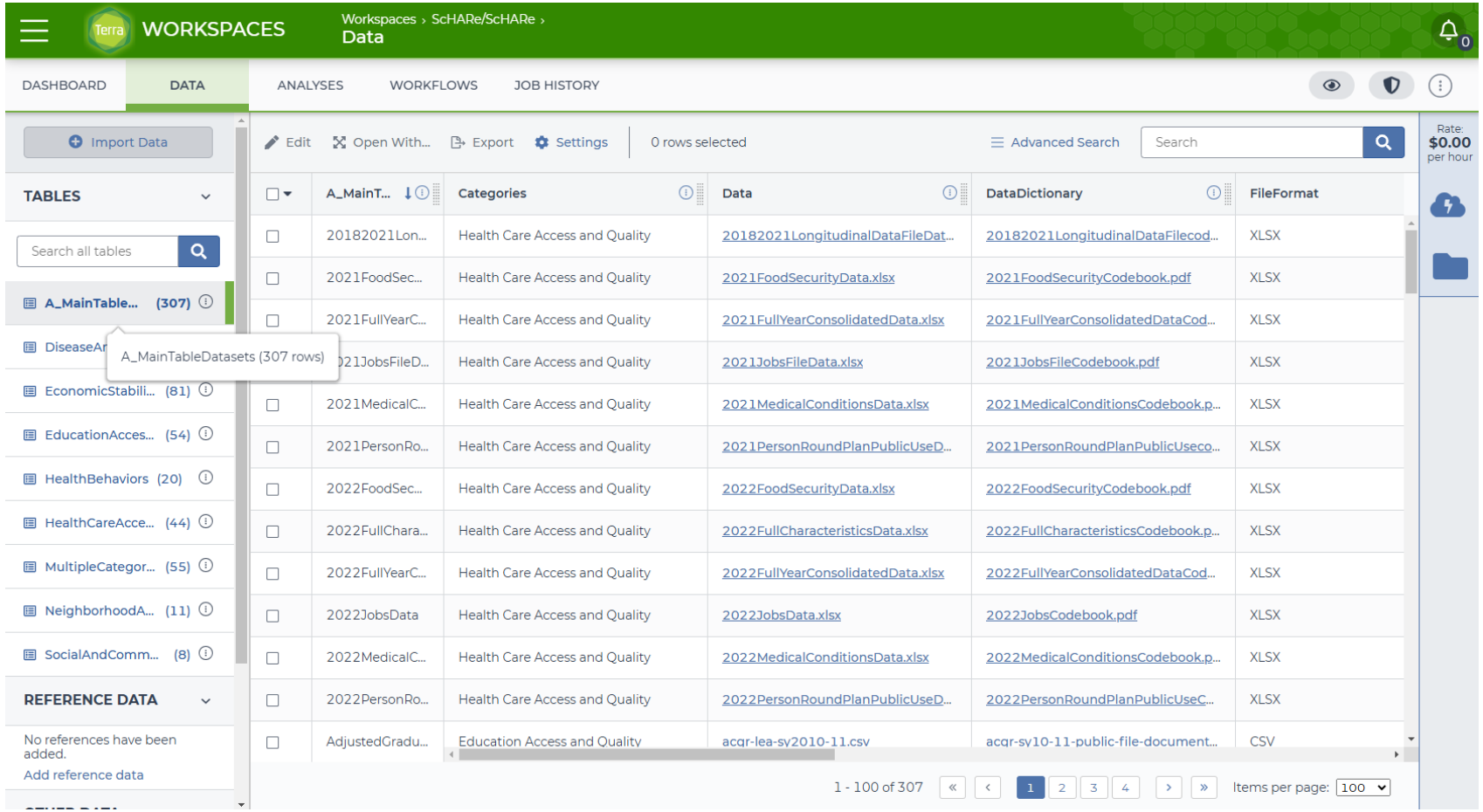
ScHARe Workspace: Analyses Tab

Your first steps

Find public datasets on the ScHARe Data Tab

Datasets hosted on SCHARE Workspace are:

- public data
- contain no personal identifiable information (PII)



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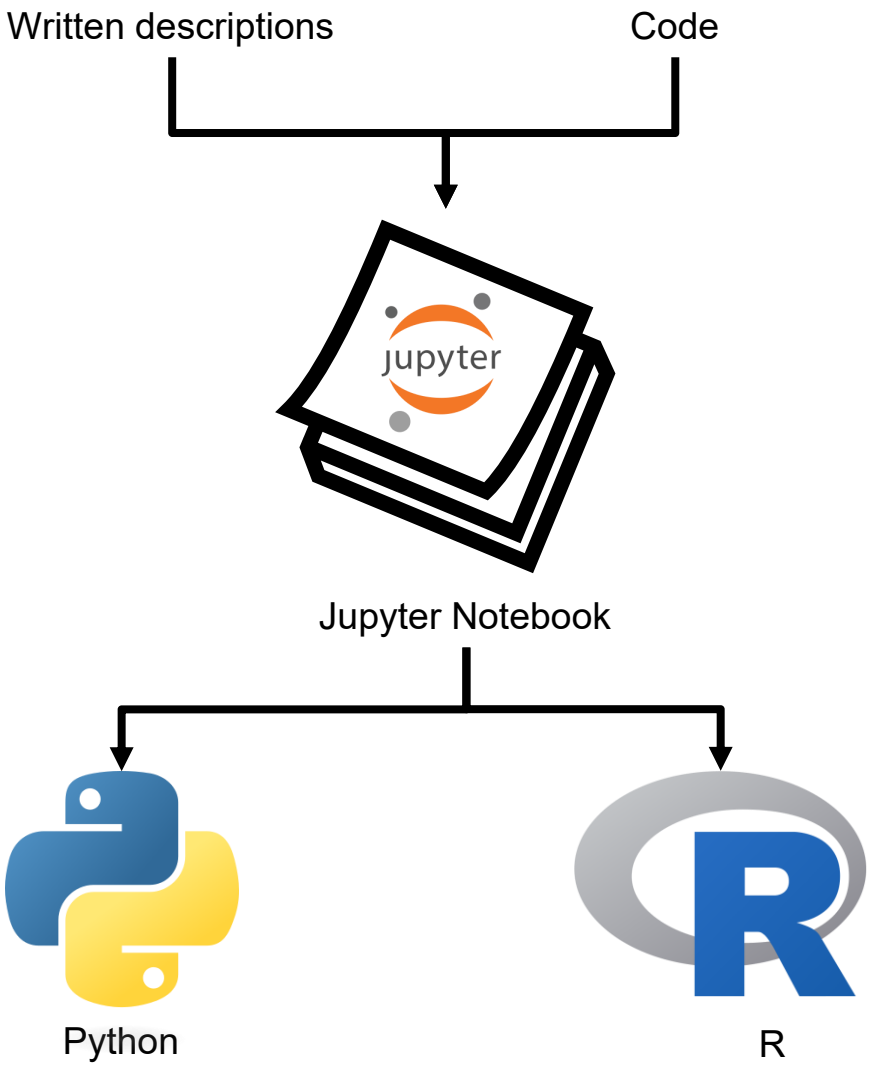
Your first steps

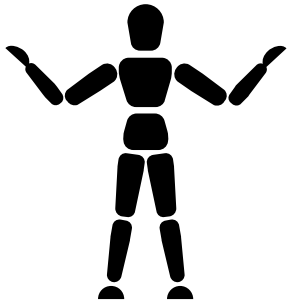
Data Analytics tools are found in the analyses tab



On the SCHARE Workspace

Reference Notebooks

Tutorial Notebooks



Model Notebooks

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Your first steps

Slido Poll

Which of the following is TRUE about the Data Tab in the SCHARE Terra Workspace?

A. The datasets have Personal Identifiable Information in them
B. The datasets are public data and are free to use
C. The datasets require a Data Use Agreement to be signed to use
D. The datasets are from untrustworthy sources

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Pull data from the ACS

Simple analysis and visualization

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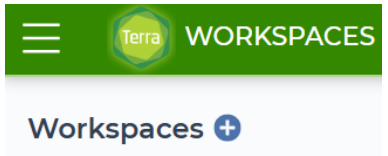
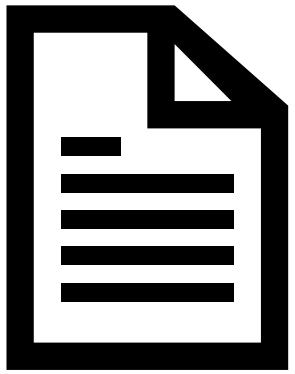


Pull data from the ACS

Simple analysis and visualization

Terra can take in data sources 3 ways

1. Upload your own data

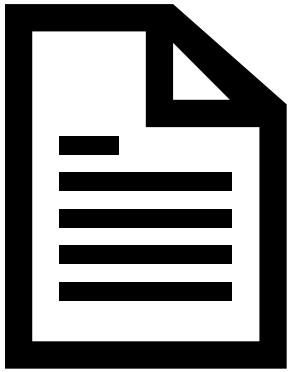


my_data.csv

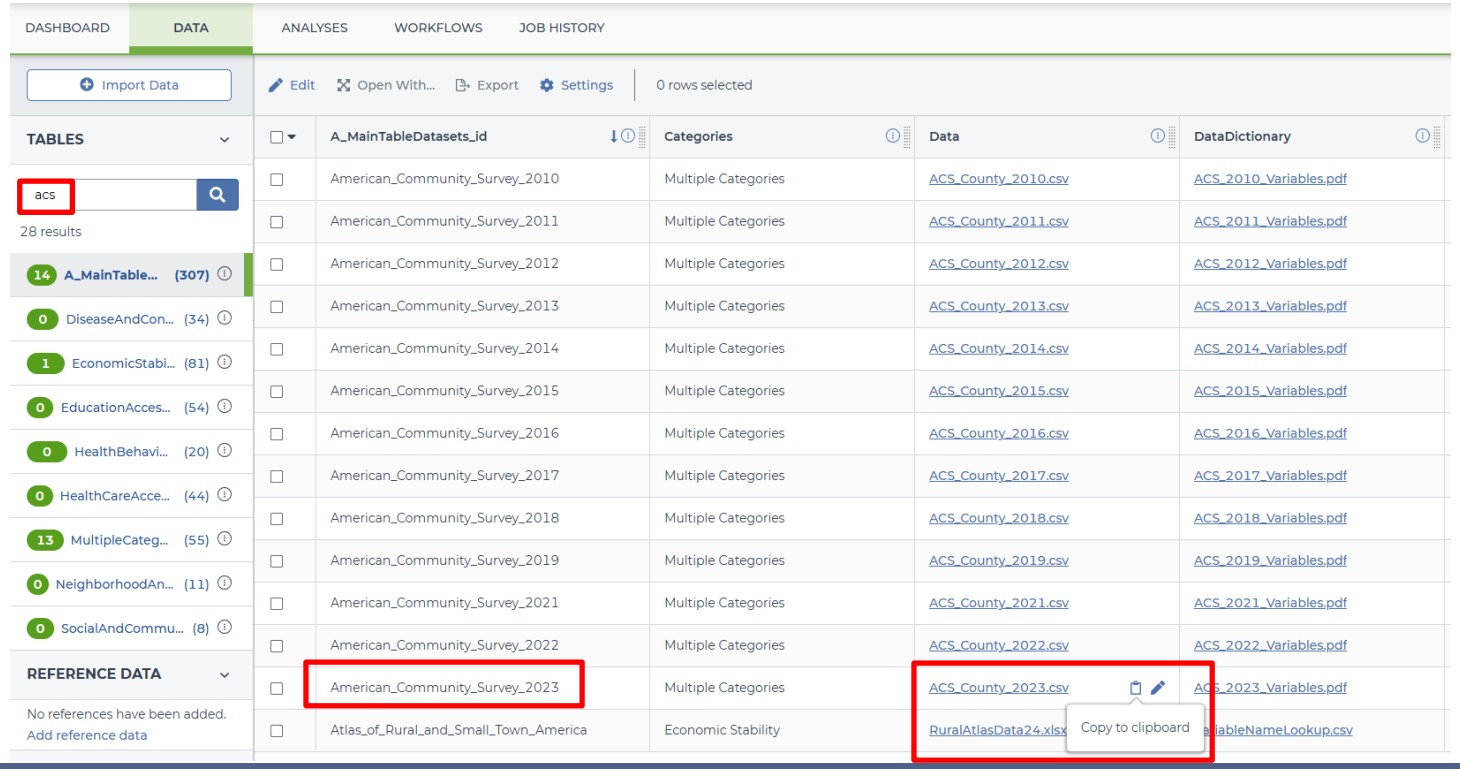
2. Pull in Google-hosted datasets

3. Use datasets on the SCHARE Workspace

Let’s pull in some data from the Census



County Data (2023)



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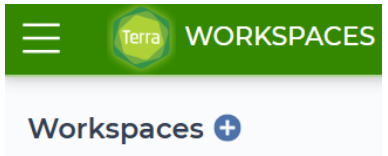


Get Census data

Simple analysis and visualization

Finally, let’s visualize some of the data in Python

Terra WORKSPACES

Finally, let’s visualize some of the data in Python

1. Copy the dataset from the SCHARE Workspace to your Workspace

```
!gsutil cp gs://fc-secure-d6e25d73-4b50-4dbc-ac10-ec689987eaa9/uploads/General/ACS_County_2023.csv .
```

2. Bring in a library of code that helps us store the data

```
import pandas as pd
```

3. Load in the dataset from the Workspace

```
data = pd.read_csv('ACS_County_2023.csv')
```

4. Take a peek at the data to see if this worked

```
data.head(10)
```

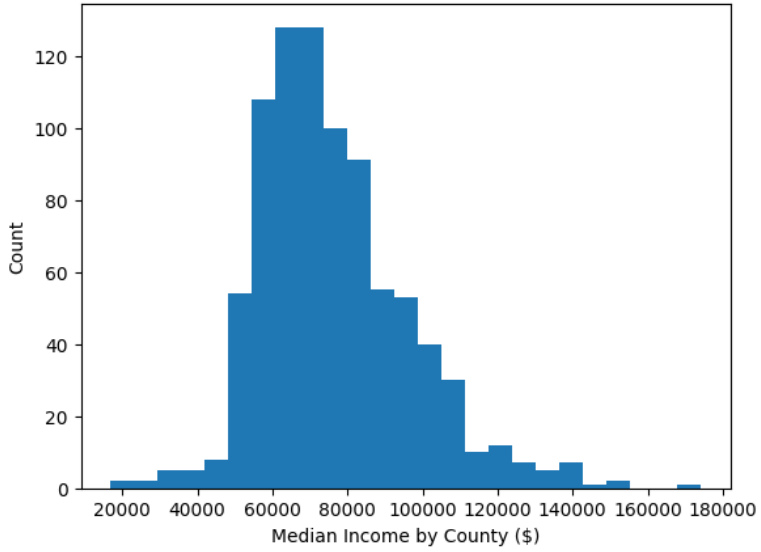
	GEO_ID	NAME	state	county	DP02_0001E	DP02_0002E	DP02_0003E	DP02_0004E	DP02_0005E	DP02_0006E	...
0	0500000US01003	Baldwin County, Alabama	1	3	105698	57455	16372	5658	2244	15984	...
1	0500000US01015	Calhoun County, Alabama	1	15	46310	20559	7325	2114	1083	8399	...
2	0500000US01043	Cullman County, Alabama	1	43	35961	19807	7399	2285	691	5868	...
3	0500000US01049	DeKalb County, Alabama	1	49	27182	14118	5138	1991	963	4965	...
4	0500000US01051	Elmore County, Alabama	1	51	33692	18114	5021	1563	404	5565	...

5. Bring in a library of code for visualization

```
import matplotlib.pyplot as plt
```

6. Make a histogram of median household income by county

```
plt.hist(data['DP03_0062E'],25)
plt.xlabel('Median Income by County ($)')
plt.ylabel('Count')
```



from the codebook:

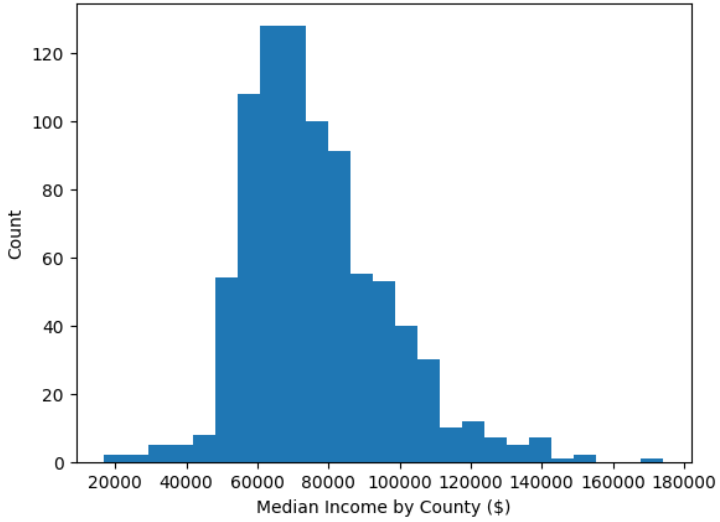
10/3/24, 8:47 PM Census Data API: /data/2023/acs/acs1/profile/variables

Name	Label	Concept	Required	Attributes	Limit	Predicate Type	Group
DP03_0061PE	Percent!!INCOME AND BENEFITS (IN 2023 INFLATION-ADJUSTED DOLLARS)!!Total households!!$200,000 or more	Selected Economic Characteristics	not required	DP03_0061PEA, DP03_0061PM, DP03_0061PMA	0	float	DP03
DP03_0062E	Estimate!!INCOME AND BENEFITS (IN 2023 INFLATION-ADJUSTED DOLLARS)!!Total households!!Median household income (dollars)	Selected Economic Characteristics	not required	DP03_0062EA, DP03_0062M, DP03_0062MA	0	int	DP03

Putting it all together on Terra

In [44]:
```
# import packages for data storage
import pandas as pd

# copy dataset from SCHARE repository
!gsutil cp gs://fc-secure-d6e25d73-4b50-4dbc-ac10-ec689987eaa9/uploads/General/ACS_County_2023.csv .

# read in dataset and preview
data = pd.read_csv('ACS_County_2023.csv')
data.head(10)
```

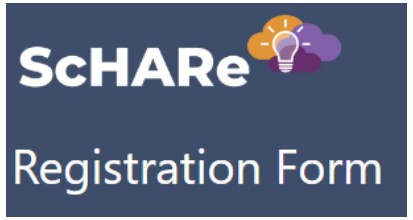
In [46]:
```
# import package to visualize data
import matplotlib.pyplot as plt

# make a histogram of median household income
plt.hist(data['DP03_0062E'],25)
plt.xlabel('Median Income by County ($)')
plt.ylabel('Count');
```



Today’s mission

Getting Set Up on Terra

Register for ScHARe



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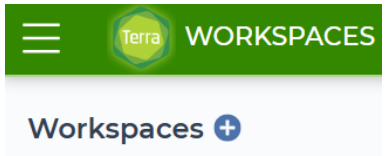


Pull data from the ACS

Simple analysis and visualization

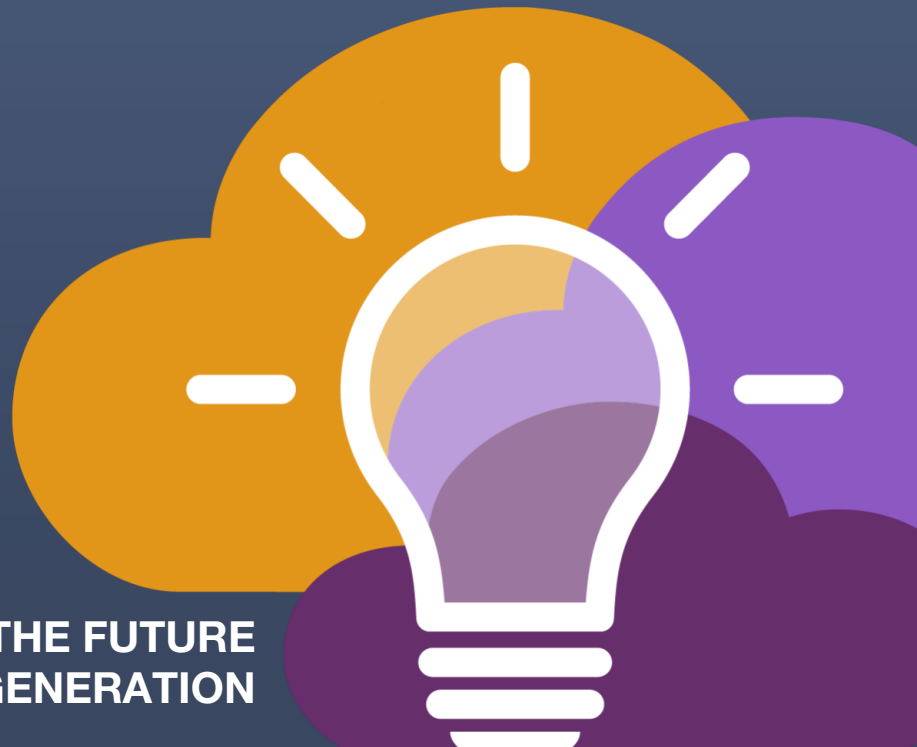
Slido Poll

Which of the following is FALSE about the Data Tab in the SCHARE Terra Workspace?

A. Terra can input your own data to use for analysis
B. You can run your own analyses in the SCHARE Workspace
C. Terra can input data from the SCHARE Workspace or Google
D. Terra currently supports writing analysis code in R or Python

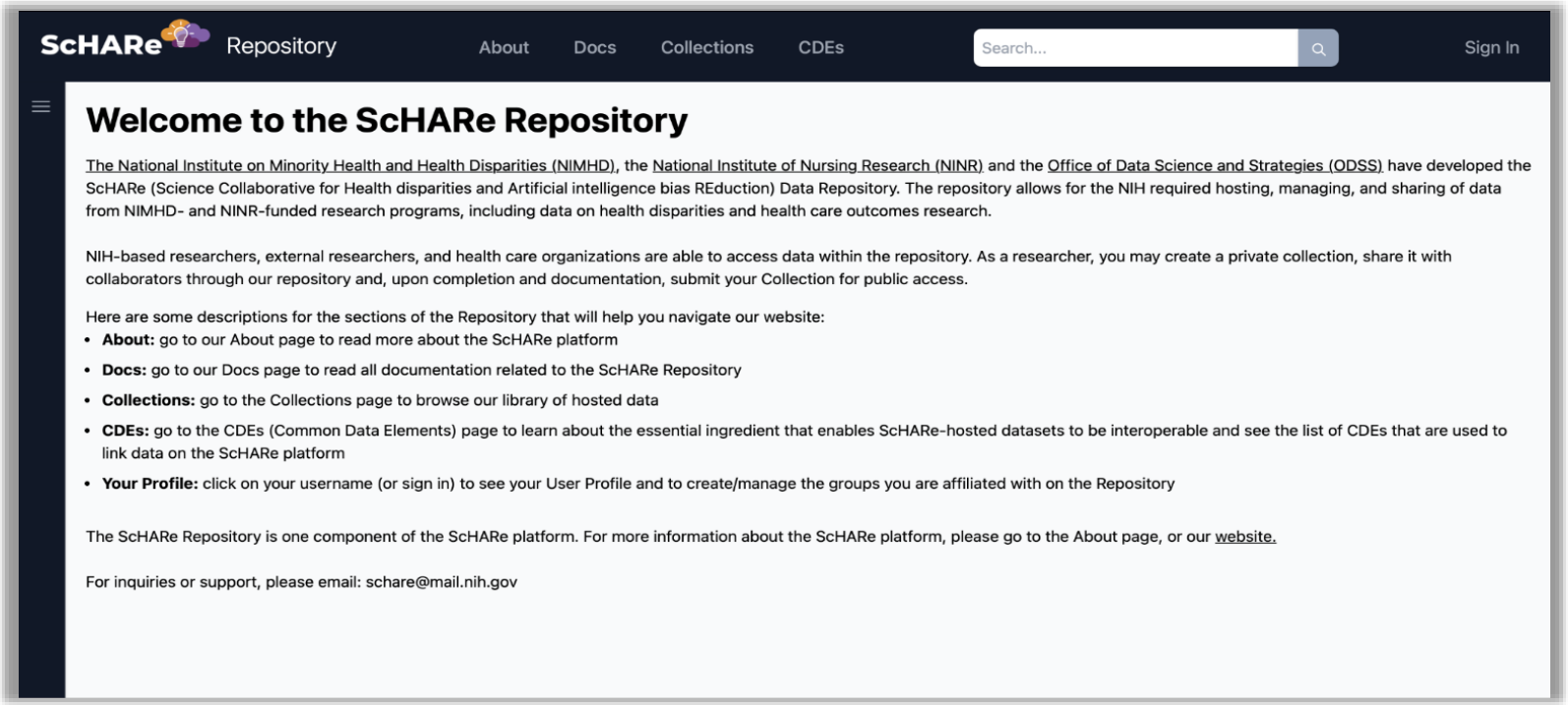
ScHARe

Repository Background



BE A PART OF THE FUTURE
OF KNOWLEDGE GENERATION

ScHARe Repository



- Host your project data in a **safe space** with privacy levels, secure workspaces, collaboration platform
- Comply with **NIH Data Management and Data Sharing Policy**
- **Focus**: Social Science, SDoH, Health Disparities, Health Outcomes Research
- **CDE centric:** Map project CDEs or variables to ScHARe-PhenX CDEs
- **Link your data** with others and federated data

What can you do with the Repository?

Upload your own data

Store collected data and annotate with a data dictionary. Align data to the ScHARe CDEs.

Harmonize data to CDEs

Map uploaded data to CDEs. Join your data with project or federated data via CDEs.

Browse for data

Find relevant federated national datasets or other project data.

Manipulate and aggregate data for analysis

Filter, sort, and select subsets for specific purposes. Link and aggregate datasets.

Control privacy levels and data sharing

Share confidential data among colleagues. Share public access data with the research community.

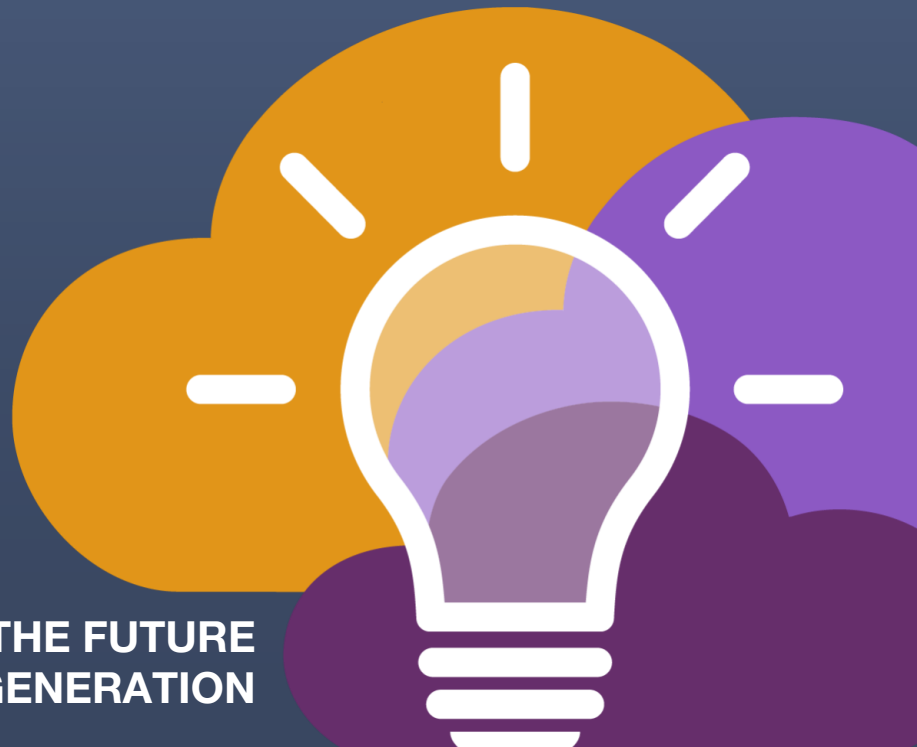
Data Analysis via ScHARe Terra or local analysis platform

Key Features of the ScHARe Repository

- Offers secure, long-term **storage** for project data
- Provides easy access to federated and other shared population science, Social Determinants of health (SDoH) **data sets**
- Leverages **CDEs** for organizing, aggregating, and harmonizing data
  - CDEs facilitate use of established semantic and coding systems
  - Aligns with ScHARe's focus on CDE centric data sharing
- Provides seamless tabular **data management**, aggregation, manipulation, and harmonization directly within the Repository
- Offers different **privacy levels** to meet individual data set requirements (public, restricted, confidential, private)
- Allows **sharing data** with other research collaborators

ScHARe

Getting Started



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Visit the ScHARe Repository!

https://schare-repository.nimhd.nih.gov/

For today's training, please use our test site:

https://test-schare.nimhd.nih.gov/

Data uploaded to this site will not be retained.

Log In to the Repository

ScHARe Repository About Docs Collections CDEs Search... Sign In

Welcome to the ScHARe Repository

The National Institute on Minority Health and Health Disparities (NIMHD), the National Institute of Nursing Research (NINR) and the Office of Data Science and Strategies (ODSS) have developed the ScHARe (Science Collaborative for Health disparities and Artificial intelligence bias REduction) Data Repository. The repository allows for the NIH required hosting, managing, and sharing of data from NIMHD- and NINR-funded research programs, including data on health disparities and health care outcomes research.

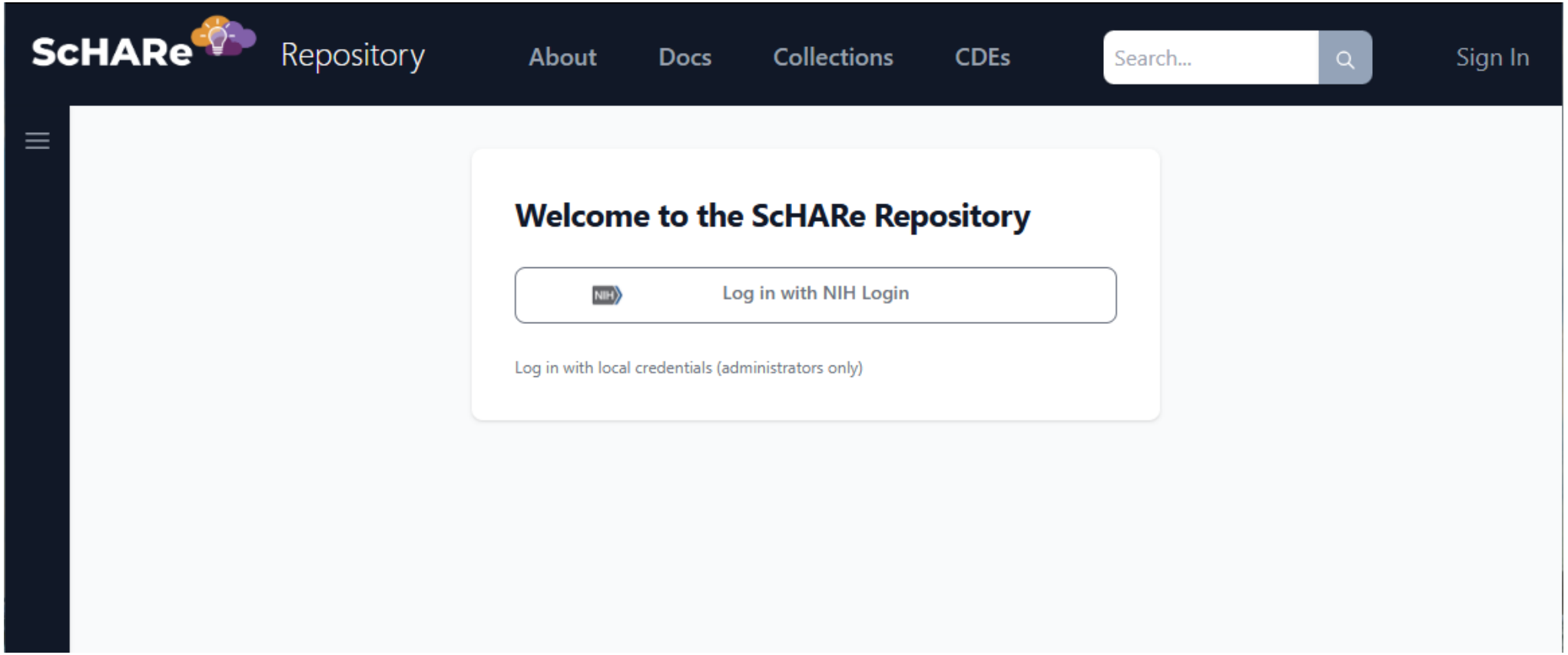
NIH-based researchers, external researchers, and health care organizations are able to access data within the repository. As a researcher, you may create a private collection, share it with collaborators through our repository and, upon completion and documentation, submit your Collection for public access.

Here are some descriptions for the sections of the Repository that will help you navigate our website:

- **About:** go to our About page to read more about the ScHARe platform
- **Docs:** go to our Docs page to read all documentation related to the ScHARe Repository
- **Collections:** go to the Collections page to browse our library of hosted data
- **CDEs:** go to the CDEs (Common Data Elements) page to learn about the essential ingredient that enables ScHARe-hosted datasets to be interoperable and see the list of CDEs that are used to link data on the ScHARe platform
- **Your Profile:** click on your username (or sign in) to see your User Profile and to create/manage the groups you are affiliated with on the Repository

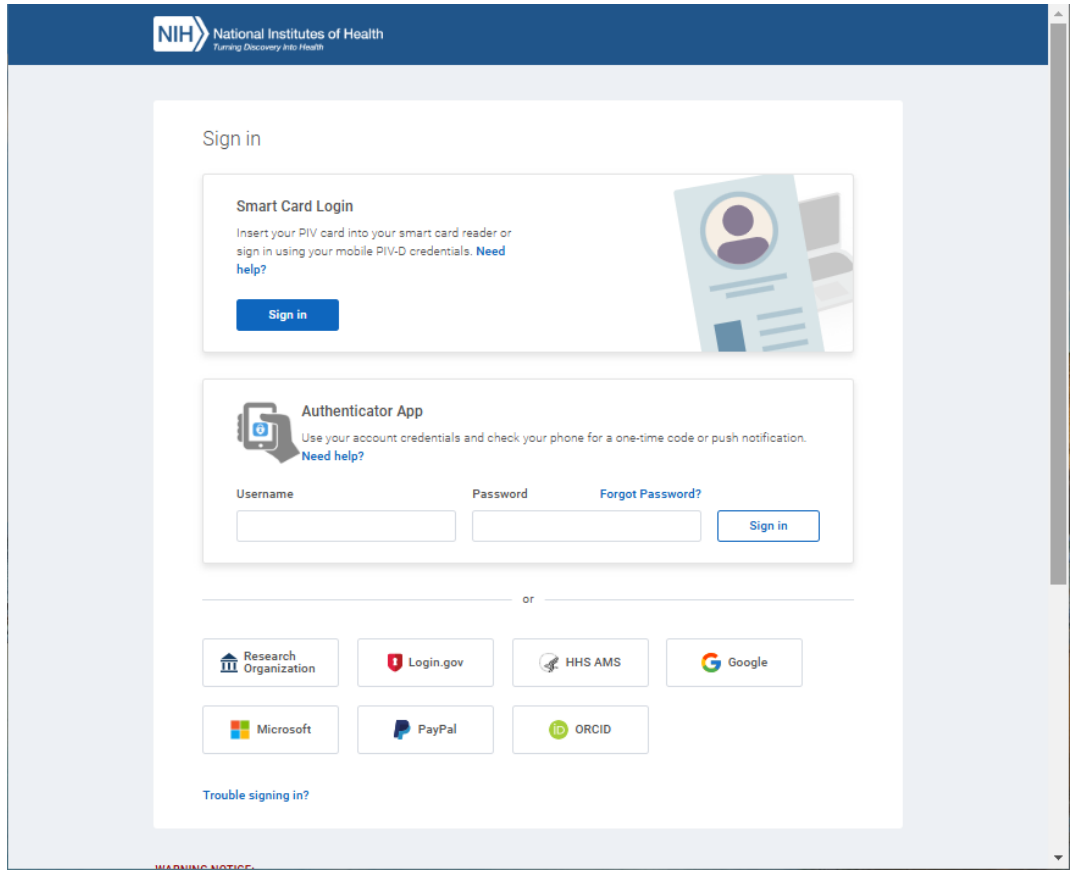
The ScHARe Repository is one component of the ScHARe platform. For more information about the ScHARe platform, please go to the About page, or our website.

Log In to the Repository



Log In to the Repository

- Select the most appropriate login method
  - NIH Smart Card Login for NIH affiliates
  - Otherwise, Research Organization, Login.gov, HHS AMS preferred



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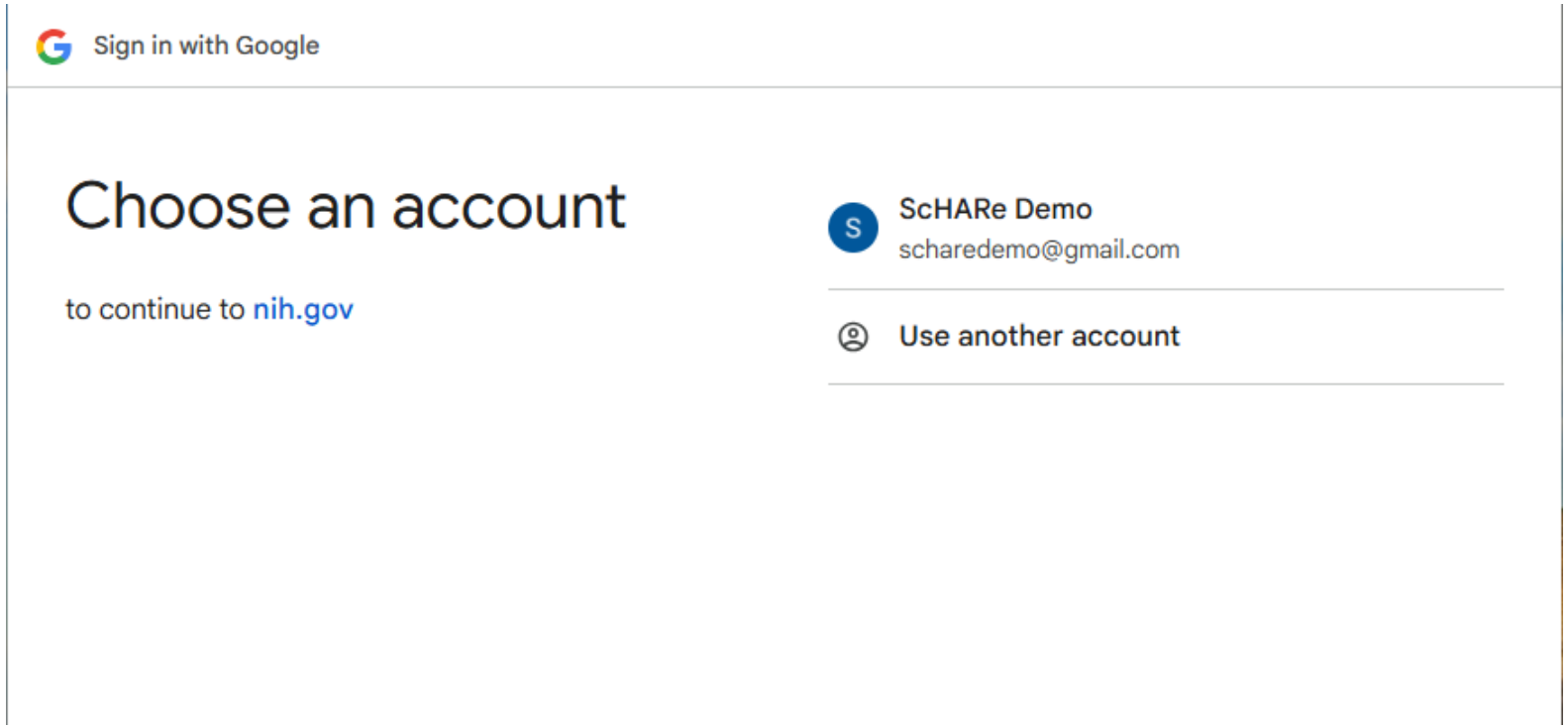

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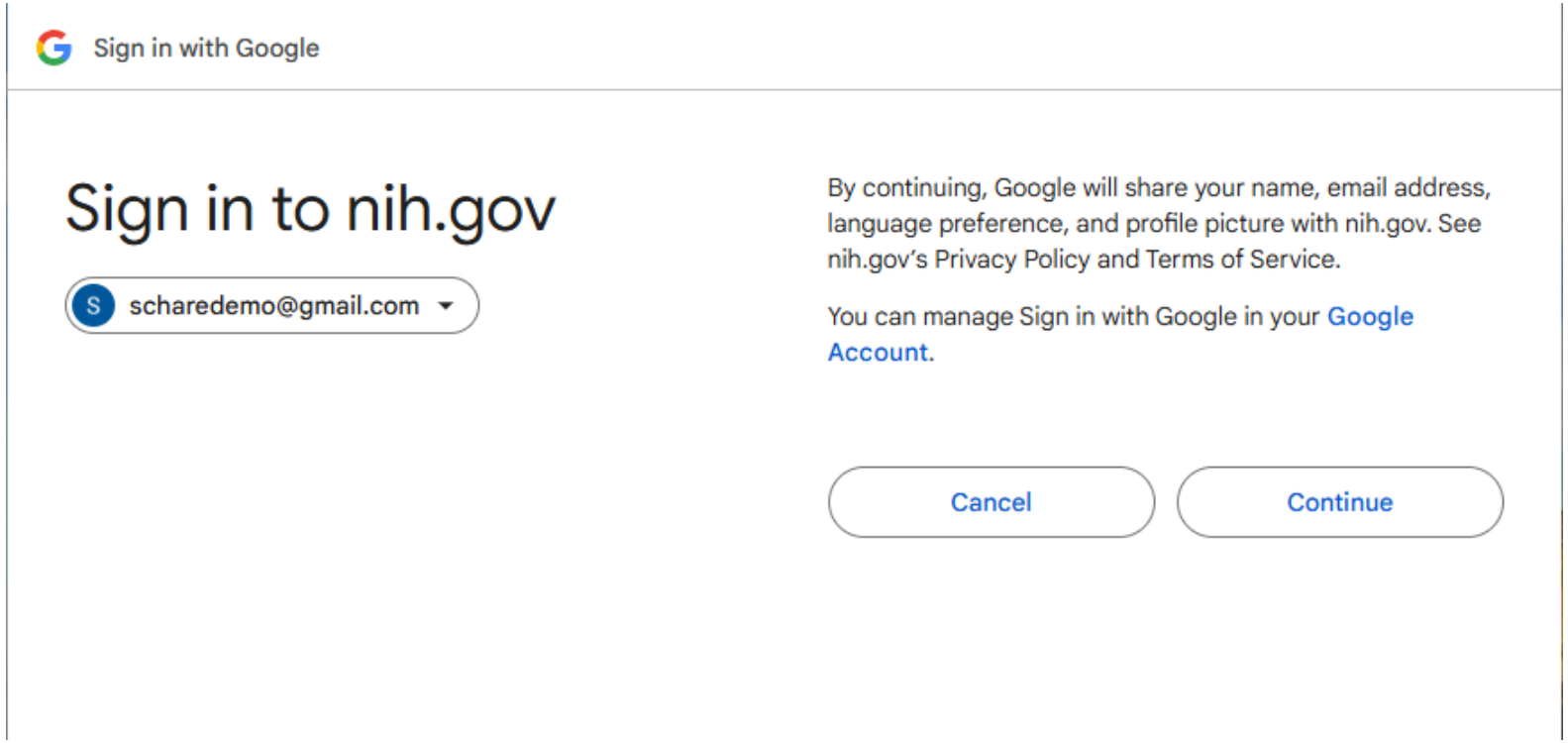

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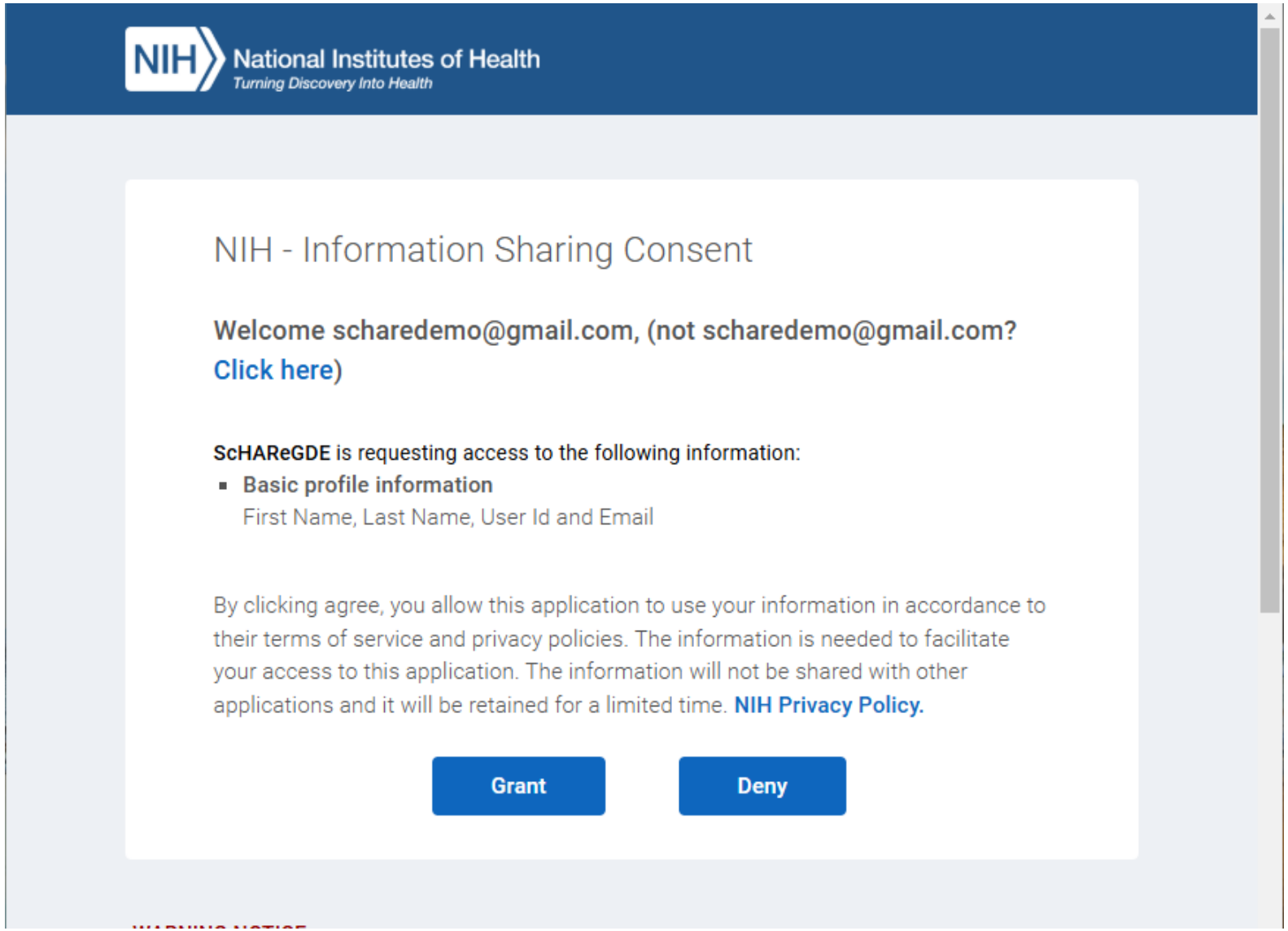

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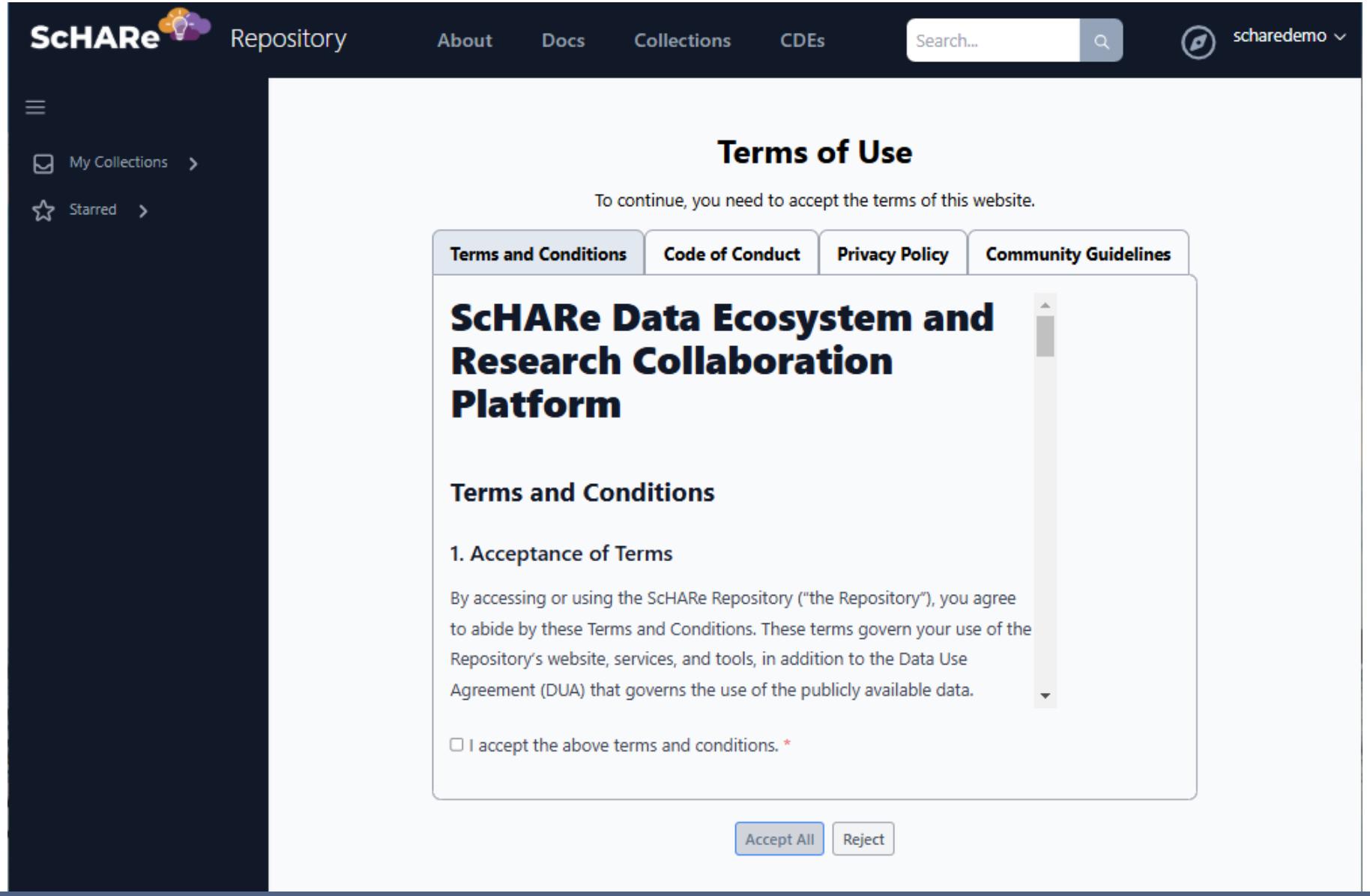

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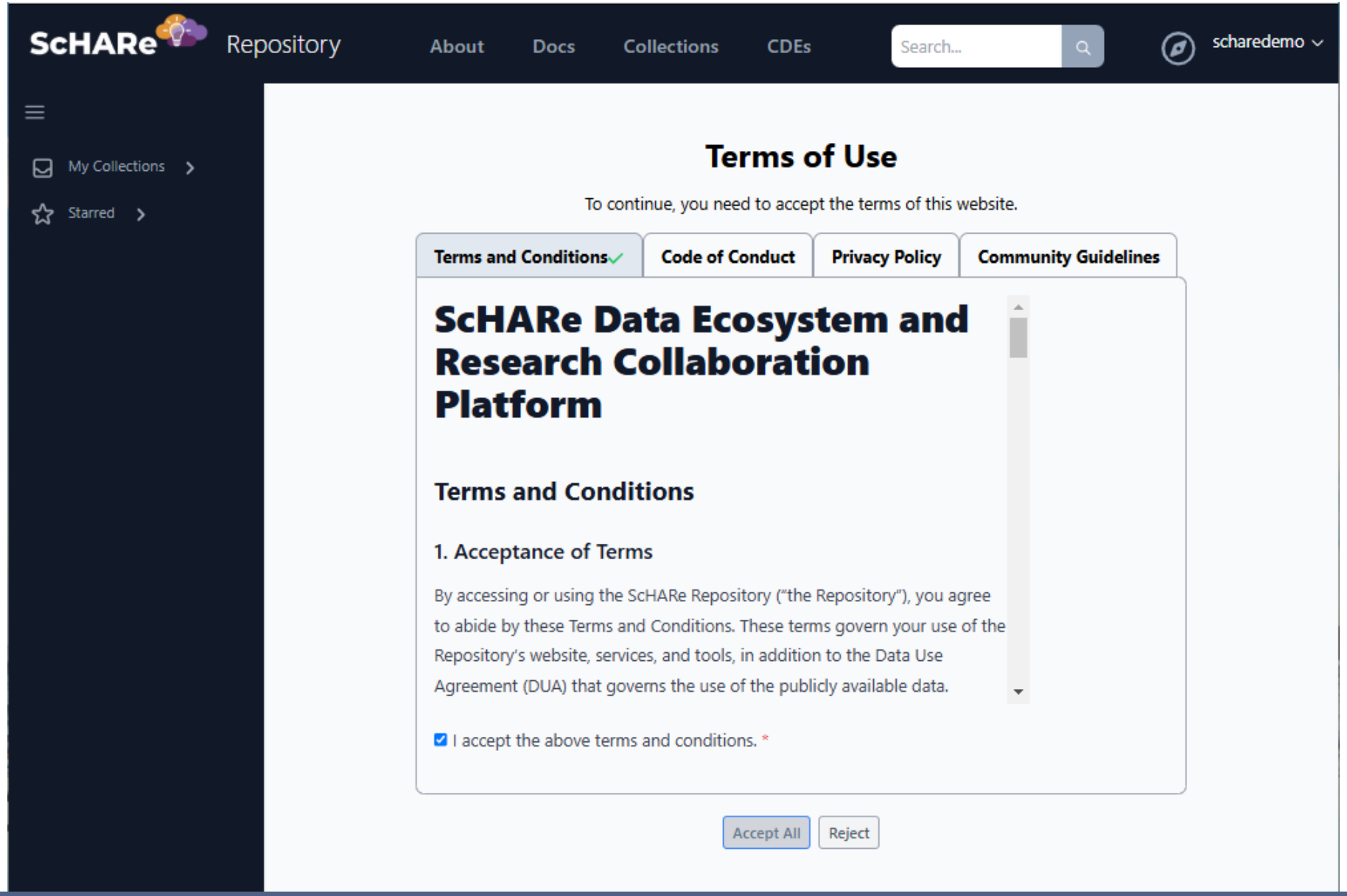

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ScHARe Data Ecosystem and Research Collaboration Platform

General Data Use Agreement

The ScHARe General Data Use Agreement sets forth principles for responsible management and use of large-scale health disparities and population health data accessed through the ScHARe Repository.

This agreement applies to all the data contained within the ScHARe Repository, including publicly accessible data along with researcher-

☑ I accept the above code of conduct. *

Accept All | Reject

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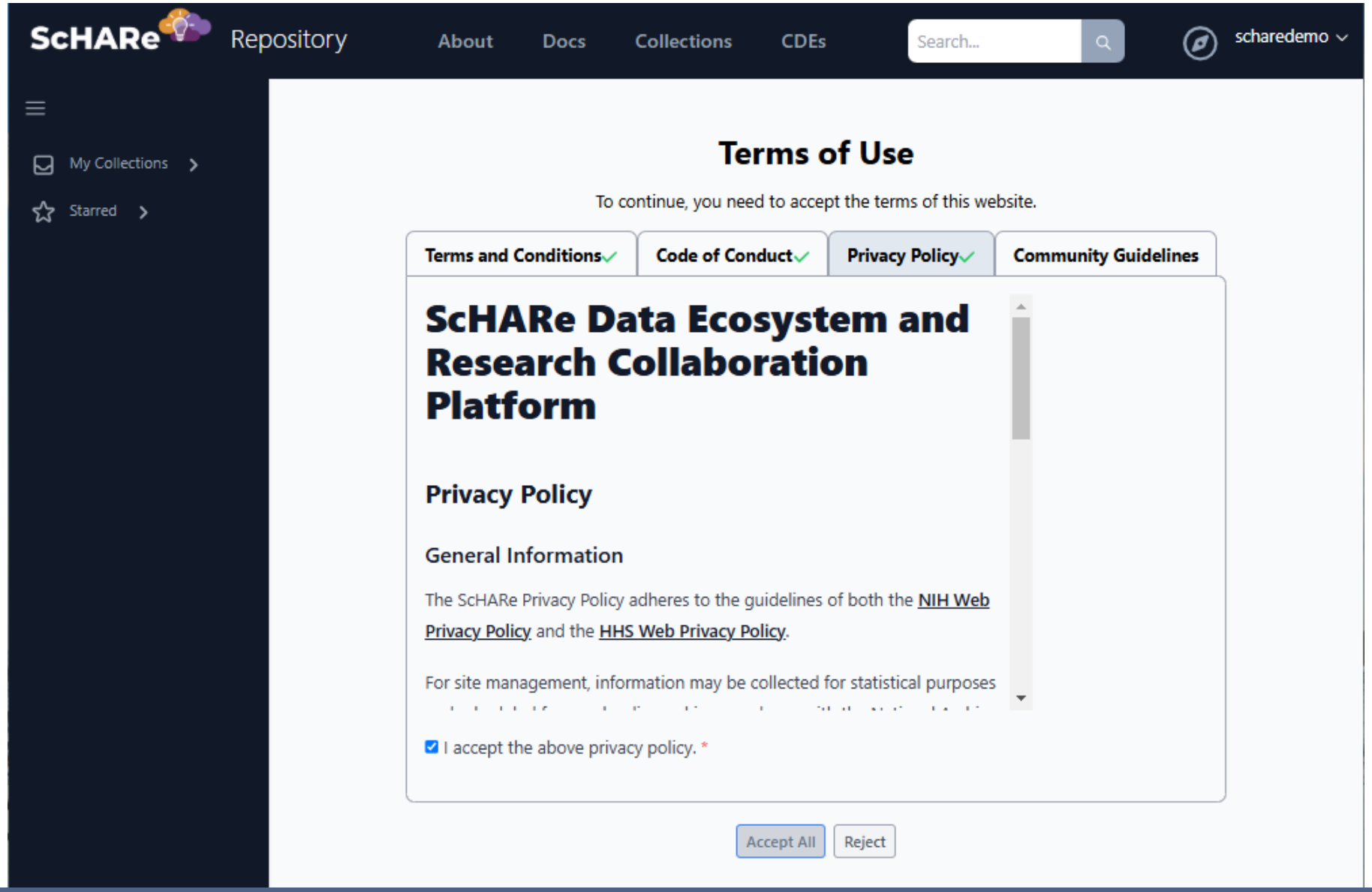

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ScHARe Data Ecosystem and Research Collaboration Platform

Community Guiding Principles

This Community Guiding Principles document outlines expectations of every member of the Science Collaborative for Health disparities and Artificial intelligence bias REduction (ScHARe) community, which includes institutions and individuals who use ScHARe resources, expertise, and data. The ScHARe community is committed to providing a welcoming and inspiring environment for all community members. Failure to abide by this

☑ I accept the above community guidelines. *

Accept All | Reject

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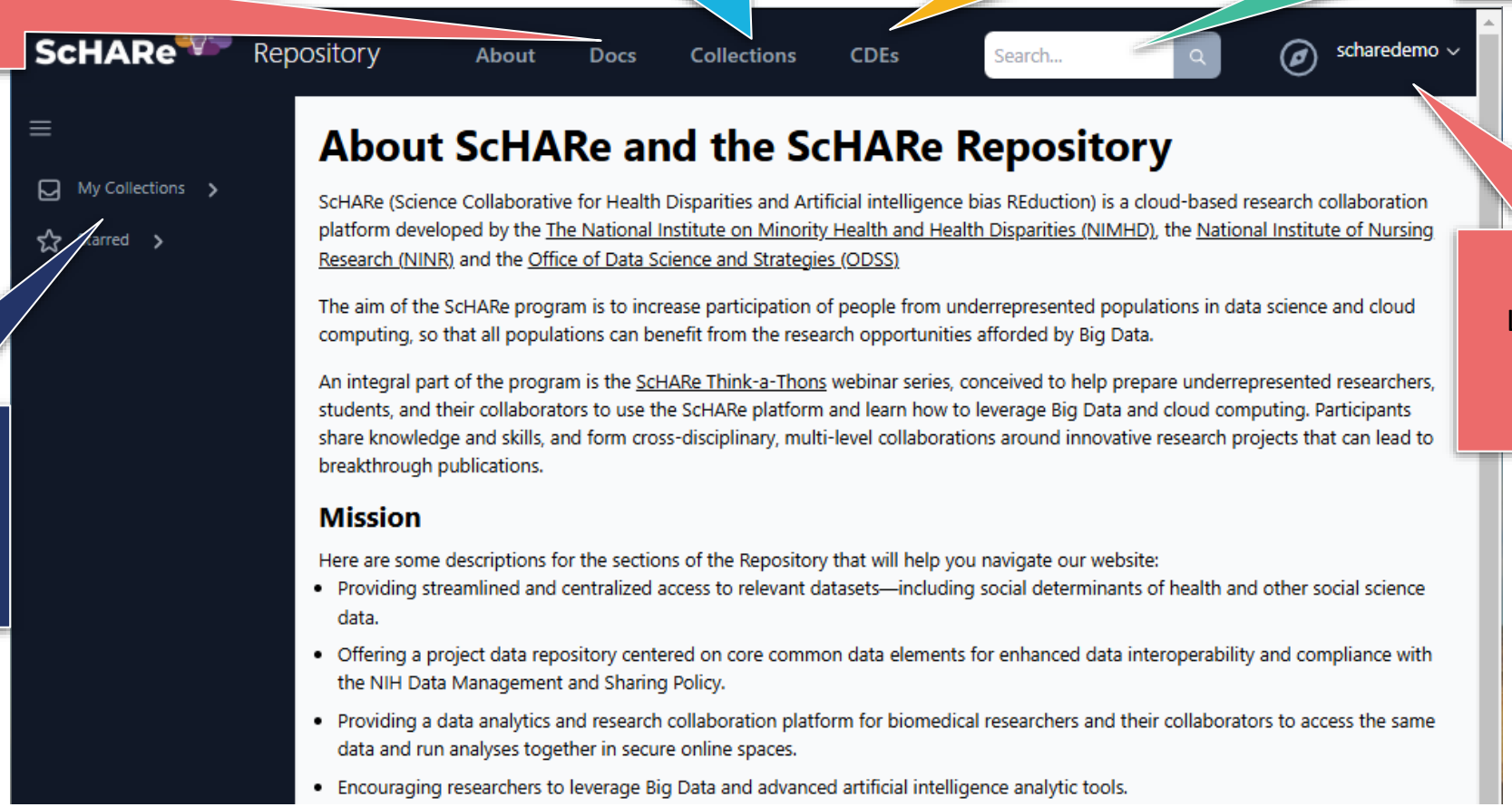
Learn more about the site

Browse for data
(private and public)

View CDE definitions

Search across all data that you can see
(private and public)



Log in, log out, and user information

Quick links to recently accessed and your own data

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These principles were established by the ScHARe Community to encourage and enable a highly collaborative research environment to address and reduce health disparities, improve health outcomes, and mitigate artificial intelligence bias. ScHARe Community members are expected to honor these guiding principles, be open to questions, reserve judgement, treat each other with respect, and foster engagement regardless of the career level or knowledge base.

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- • • Keeping on Track
- • • Audio and Visual Presence
- • • Public and Private Messaging
- • • Respect and Communicate team and personal boundaries.
- • • Resolving Issues and Conveying Concerns
- • General Data Use

ScHARe Repository - Collections

ScHARe Repository

About | Docs | Collections | CDEs | Search... | scharedemo

My Collections

Starred

Collections

Create New Collection

My Collections

You don't have any collections yet - why not create a new one using the button above?

Shared with Me

You don't have any collections shared with you right now!

Public Collections

grouped by: Domains of Influence

Biological

Example NMHSS Analysis LIVE

This contains data from the 2018 National Mental Health Services Survey (N-MHSS)...

7 months ago

ScHARe Repository - CDEs

ScHARe Repository

About | Docs | Collections | CDEs

Search...

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My Collections

Starred

Common Data Elements

A major obstacle in advancing health disparities research is linking data between different studies. To surmount this, the ScHARe Repository makes use of a set of shared language, definitions, and an internal reference system associated with common categories in health disparities data. This system is known as Common Data Elements (CDEs), and the use of CDEs across the Repository enables the linking of datasets and a new generation of health disparities research.

The ScHARe Repository leverages the following CDE sets:

ScHARe

19 CDEs

ScHARe core common data elements

Age

Age ›	number	5 definitions	1 concept	PDjBiGXjO:0001
Age Units ›	string	5 definitions	1 concept	valueSet	GNVoEdFQR0:0001

Birthplace

Birthplace - US ›	string	5 definitions	3 concepts	0qP44x2oX:0001
Birthplace - Country Outside US ›	string	4 definitions	2 concepts	_qZulkipzA:0001

ScHARe Repository - User Profile

ScHARe Repository

About | Docs | Collections | CDEs

Search...

scharedemo

Signed in as **scharedemo**

Sign out

My Collections

Starred

Common Data Elements

A major obstacle in advancing health disparities research is linking data between different studies. To surmount this, the ScHARe Repository makes use of a set of shared language, definitions, and an internal reference system associated with common categories in health disparities data. This system is known as Common Data Elements (CDEs), and the use of CDEs across the Repository enables the linking of datasets and a new generation of health disparities research.

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ScHARe 19 CDEs

ScHARe core common data elements

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Age Units ›	string	5 definitions	1 concept	valueSet	GNVoEdFQR0:0001

Birthplace

Birthplace - US ›	string	5 definitions	3 concepts	0qP44x2oX:0001
Birthplace - Country Outside US ›	string	4 definitions	2 concepts	_qZulkipzA:0001

Postal Zip Code ›	string	5 definitions	1 concept	eT7V_ETn_6:0001

ScHARe Repository - User Profile

ScHARe Repository

About Docs Collections CDEs

Search...

scharedemo

My Collections

Starred

User Profile: ScHARe Demo

User Details

Username	scharedemo
User email	scharedemo@gmail.com
Subject ID	436625d1-348c-4144-8d9f-2ec00283bc1c
Account ID	a:9f51e3d7-40f0-4b9a-95c2-a5c7d483a9a3
First Login	10 minutes ago

Profile Visibility

Your user profile's visibility controls what others see when they search for you on this site or when they view data that you have published such as public collections. Your options are:

- **Public** - Your full name and username will be visible to all users, including users who are not logged in.
- **Unlisted** - Your profile will only be visible to users who are logged in and who are members of a group that you are a member of.

Visibility: Public

Update profile visibility

ScHARe Repository - User Profile

ScHARe Repository

About Docs Collections CDEs

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scharedemo

My Collections

Starred

User Profile: ScHARe Demo

User Details

Username	scharedemo
User email	scharedemo@gmail.com
Subject ID	436625d1-348c-4144-8d9f-2ec00283bc1c
Account ID	a:9f51e3d7-40f0-4b9a-95c2-a5c7d483a9a3
First Login	11 minutes ago

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Visibility: Unlisted

Update profile visibility

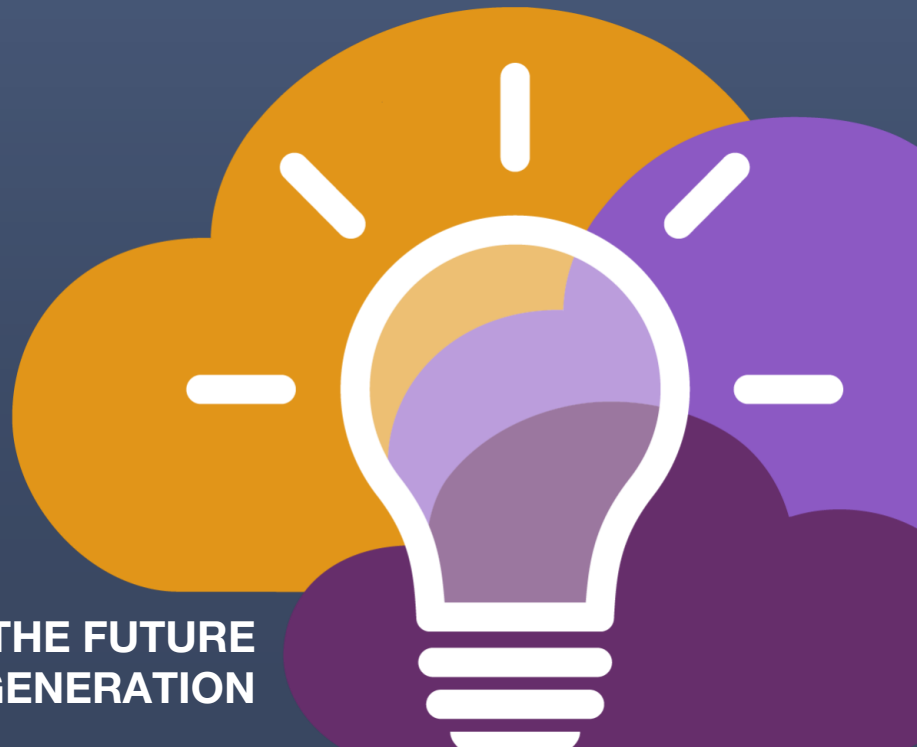
ScHARe Repository
Introduction

November 20, 2024

Deborah Duran, PhD · NIMHD
Elif Dede Yildirim, PhD · NIMHD
Mark Aronson, PhD · NIMHD

ScHARe

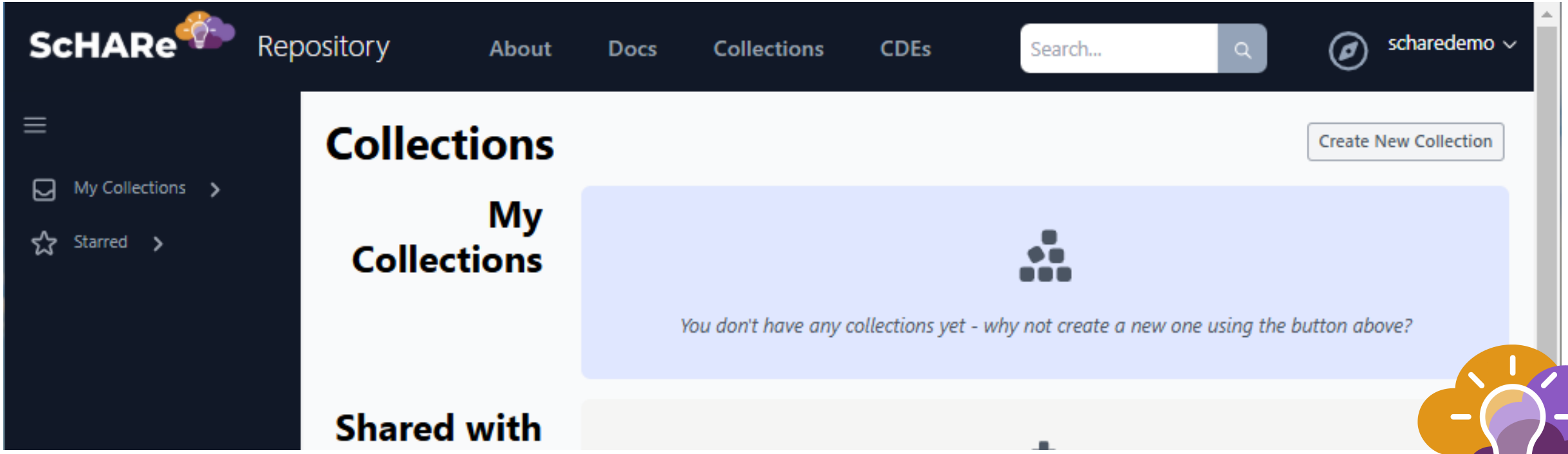
Creating a Collection



BE A PART OF THE FUTURE
OF KNOWLEDGE GENERATION

Creating a Collection

- **Collections** are a place where you can describe and store your data and any related metadata. They can be shared with colleagues and published when you're ready. You can upload any file type!
- The first step in uploading data is to create a collection



Creating a Collection

ScHARe Repository

About Docs Collections CDEs

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Recent

My Collections

Starred

Create New Collection

Newly created collections are private by default

Collection Name

CDE Set

ScHARe (19 CDEs)

Abstract

- Provide a readable name and a brief abstract (description) of the data to be uploaded
- These details can be updated later if needed

Domains of Influence

Select all that apply...

Creating a Collection

ScHARe Repository

About Docs Collections CDEs

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Recent

My Collections

Starred

Create New Collection

Newly created collections are private by default ›

Collection Name

demo-files

CDE Set

ScHARe (19 CDEs)

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Enter a Tag

Project CDEs

Levels of Influence

Select all that apply...

Domains of Influence

Select all that apply...

Research Areas

Select all that apply...

Creating a Collection

ScHARe Repository

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Common Data Elements

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ScHARe 19 CDEs

ScHARe core common data elements

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Birthplace

Birthplace - US ›	string	5 definitions	3 concepts	0qP44x2oX:0001
Birthplace - Country Outside US ›	string	4 definitions	2 concepts	_qZ

Tags

My Collections

Starred

Collection Name

demo-files

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Enter a Tag

Adolescents

Age

Alcohol Use

American Indian or Alaska Native

Asian or Asian American

Black or African American

Children

Chronic Diseases

Clinical Trial Data

Community Health Programs

County-Level Data

Data Science: AI/ML/LLM

Data from Electronic Health Records (EHRs)

Diet and Nutrition

Disability

Discrimination and Racism

Select all that apply...

Select all that apply...

Select all that apply...

Advanced User-Defined Metadata

Submit

Cancel

Apply relevant tags and project-level CDEs to your dataset

Tags

My Collections

Starred

Collection Name

demo-files

CDE Set

ScHARe (19 CDEs)

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Cross-Sectional Study ×

State-Level Data ×

Enter a Tag

Project CDEs

Levels of Influence

Select all that apply...

Domains of Influence

Select all that apply...

Research Areas

Select all that apply...

Research Focus

Select all that apply...

Advanced User-Defined Metadata ›

Submit

Cancel

Project-Level CDEs: Levels of Influence

My Collections

Starred

Collection Name

demo-files

CDE Set

ScHARe (19 CDEs)

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Cross-Sectional Study ×

State-Level Data ×

Enter a Tag

Project CDEs

Levels of Influence

Select all that apply...

Domains of Influence

Research Areas

Research Focus

Select all that apply...

- Individual
- Interpersonal
- Community
- Societal

Advanced User-Defined Metadata

Submit

Cancel

Project-Level CDEs: Domains of Influence

Starred

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Cross-Sectional Study × State-Level Data ×

Enter a Tag

Project CDEs

Levels of Influence: Individual

Domains of Influence: Sociocultural Environment

- Biological
- Behavioral
- Physical/Built Environments
- ✓ Sociocultural Environment
- Health Care Systems and Clinical Care

Research Areas

Research Focus

Advanced User-Defined Metadata ›

Submit Cancel

Project-Level CDEs- Research Areas

Starred

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Cross-Sectional Study × State-Level Data ×

Enter a Tag

Project CDEs

Levels of Influence: Individual

Domains of Influence: Sociocultural Environment

Research Areas: *Select all that apply...*

Research Focus

- Minority health study focused on a one race or ethnic population and not addressing a health disparity.
- Health Disparity Outcomes
- Other Health Outcomes / Healthcare Delivery

Advanced User-Defined Metadata ›

Submit Cancel

Project-Level CDEs: Research Focus

Starred

Abstract

November 20 Think-a-Thon Demonstration Files

Tags

Cross-Sectional Study × State-Level Data ×

Enter a Tag

Project CDEs

Levels of Influence: Individual

Domains of Influence: Sociocultural Environment

Research Areas: Select all that apply...

Research Focus: Select all that apply...

- Higher incidence and/or prevalence of disease, including earlier onset or more aggressive progression of disease
- Premature or excessive mortality from specific health conditions
- Greater global burden of disease, such as Disability Adjusted Life Years (DALY), as measured by population health metrics

Advanced User-Defined Metadata ›

Submit Cancel

The Collection Main Page

ScHARe Repository

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Collection was successfully created.

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November 20 Think-a-Thon Demonstration Files

Levels of Influence
Individual

Domains of Influence
Sociocultural Environment

Links and Documents

Data Items

Metadata and Statistics

Access Level

Private

Analysis Readiness

Not Ready

CDE Compliance - ScHARe

0 / 19 CDEs assi

The Collection Main Page

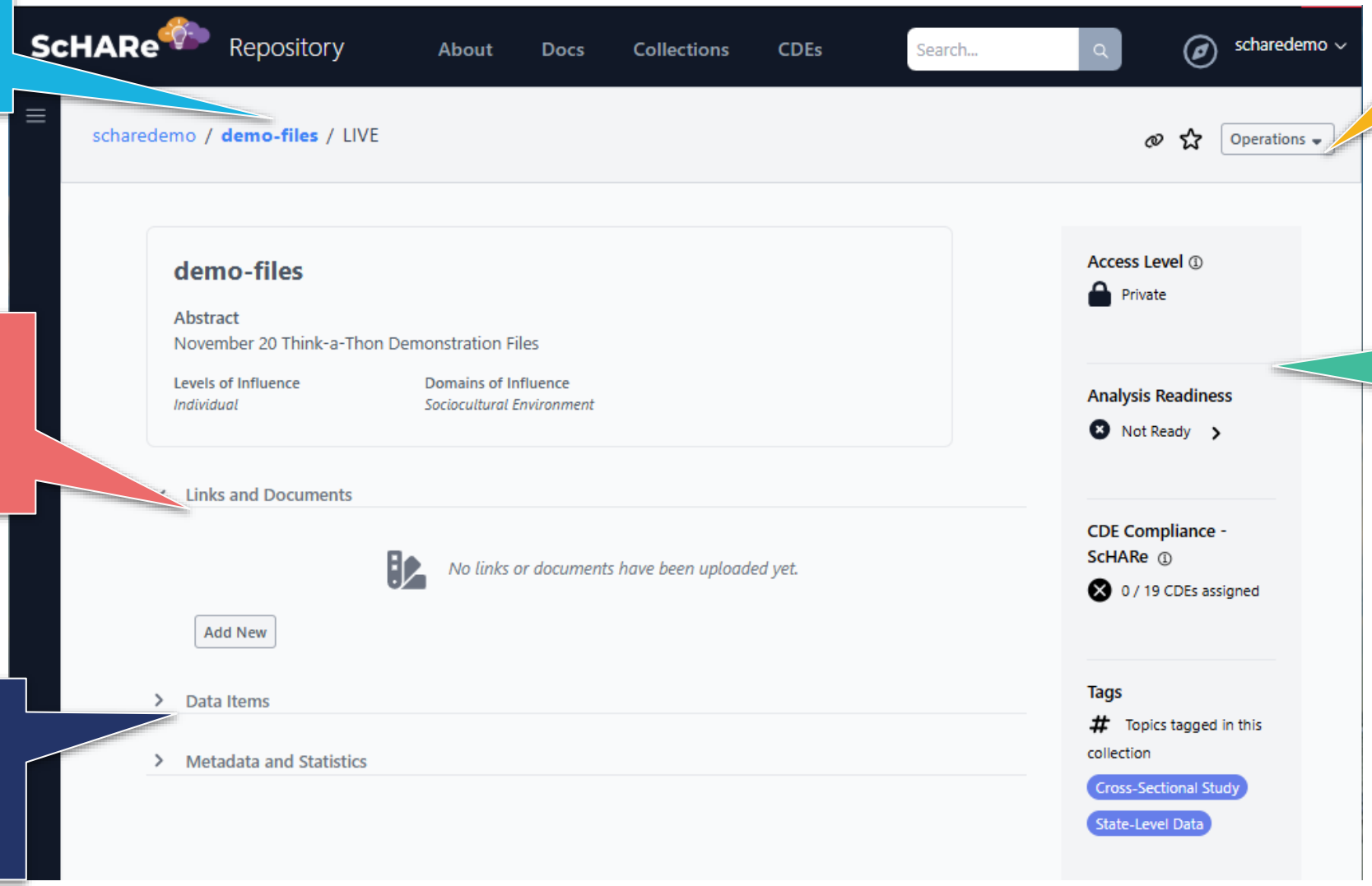
Click the collection name to return to the main page

Actions on the collection itself (edit metadata, share, delete)

Sidebar with key information

Browse and upload documentation

Browse and upload data items



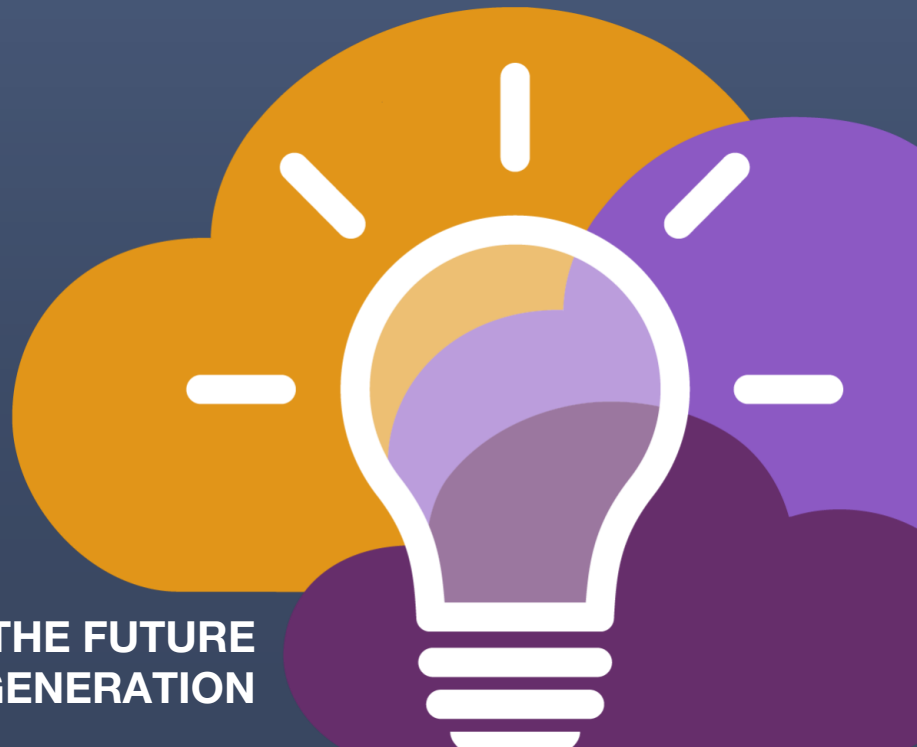
Slido Poll

Which of the following data types are you most comfortable sharing publicly?

a) Health data
b) Environmental data
c) Behavioral data
d) Other

ScHARe

Uploading your first Data Set



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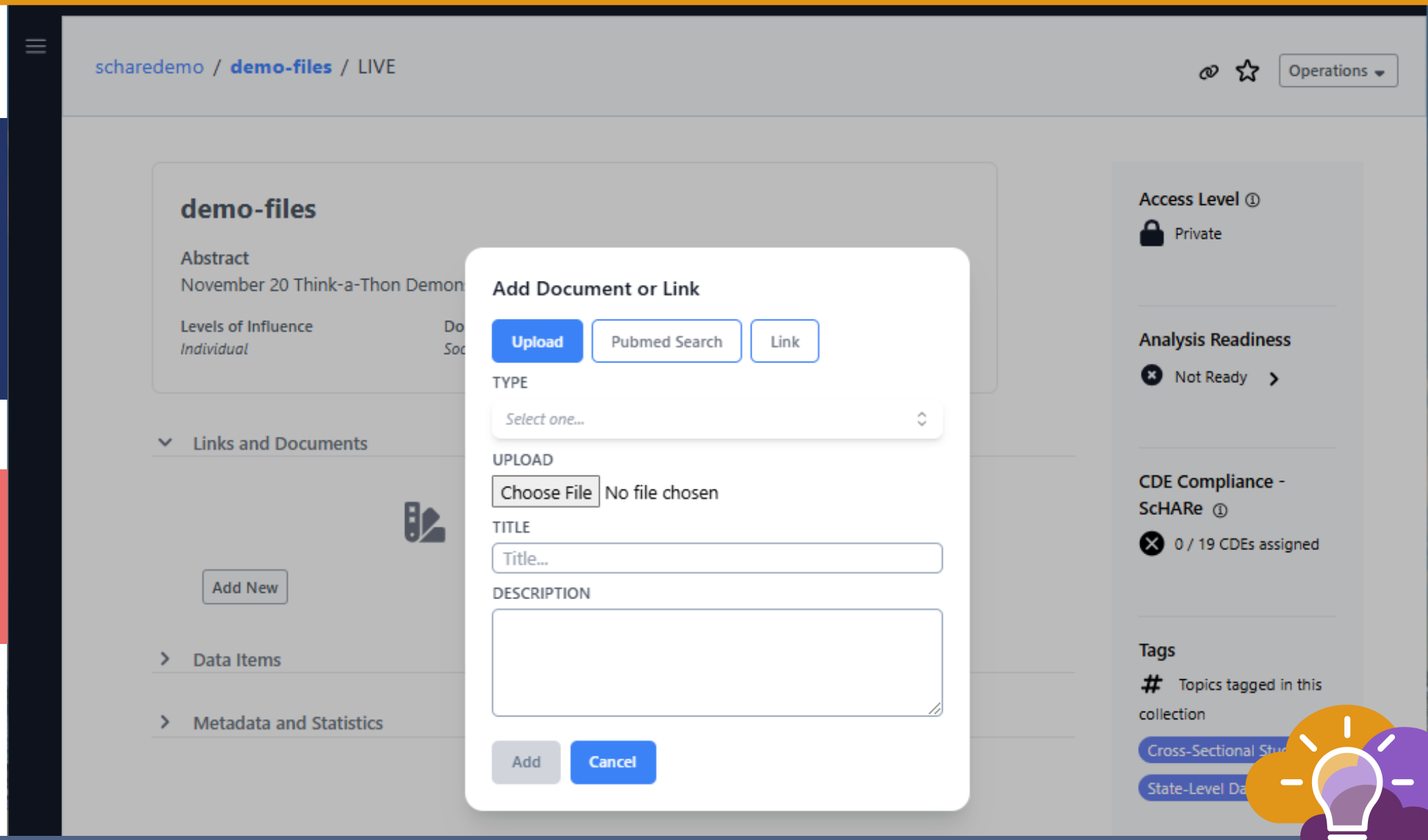
Uploading a Data File

Upload any document, presentation, etc.

Link to papers through PubMed



Uploading a Data File

You can upload to the ScHARe Repository…

Any file

- Documents (PDF, docx, etc.)
- Archives (zip, etc.)

Some file formats can be previewed in the web interface

Anything uploaded can be downloaded

Tabular data

- CSV and TSV
- Excel (xlsx, xls)
- SAS (XPORT V5/6, not V8)
- SPSS
- STATA
- Parquet

Tabular data can be viewed in the web interface, plus much more…

Uploading a Data File

ScHARe Repository

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November 20 Think-a-Thon Demonstration Files

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Individual

Domains of Influence
Sociocultural Environment

Links and Documents

Data Items

Drag and Drop or Browse Files to Upload

Metadata and Statistics

Access Level

Private

Analysis Readiness

Not Ready

CDE Compliance - ScHARe

0 / 19 CDEs assigned

Tags

Topics tagged in this collection

Cross-Sectional Study

State-Level Data

Uploading a Data File

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November 20 Think-a-Thon Demonstration Files

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Sociocultural Environment

Links and Documents

Data Items

Drag and Drop or Browse Files to Upload

exa...csv

Upload Files

Cancel All

Metadata and Statistics

Access Level
Private

Analysis Readiness
Not Ready

CDE Compliance - ScHARe
0 / 19 CDEs assigned

Tags
Topics tagged in this collection

Cross-Sectional Study
State-Level Data

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Levels of Influence
Individual

Don
Soci

Links and Documents

Data Items

STATUS	NAME	SIZE
	example_data.csv	25 KB

Page 1 of 1

Drag and Drop or Browse Files to Upload

Metadata and Statistics

File Upload Complete

The ScHARe Repository uses the ScHARe common data elements to enable data discovery, linking, and interoperability. To make your data more interoperable and ready for publication, we will guide you through the process of assigning common data elements to your data column headings. Click OK to continue.

TIP: You can cancel now and complete the process later using the "Configure CDEs" tool from the collection Operations menu.

OK Cancel

Access Level
Private

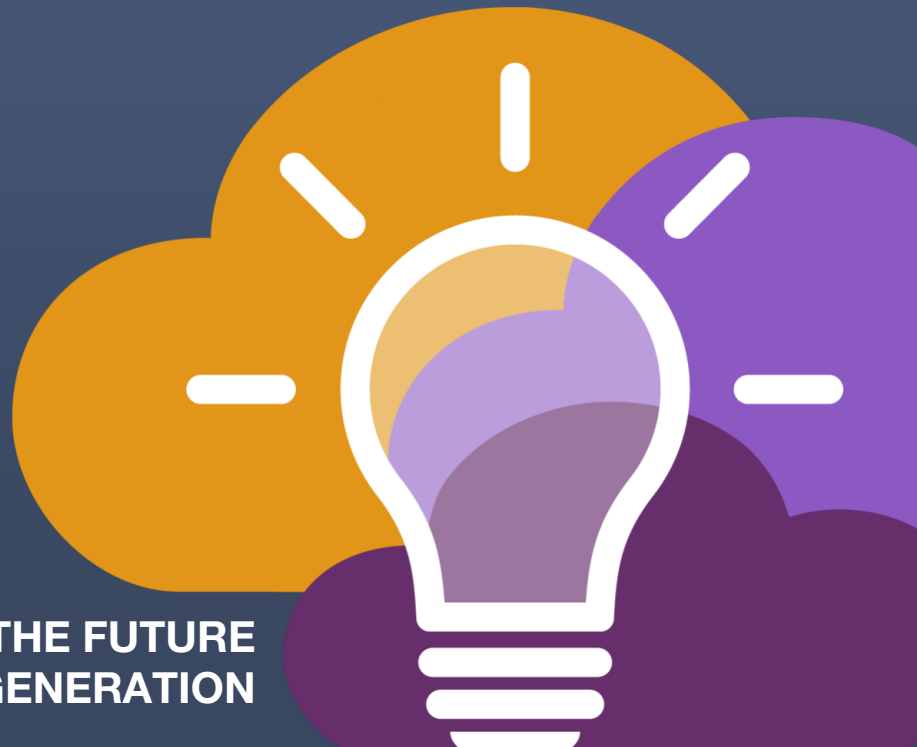
Analysis Readiness
Not Ready

CDE Compliance - ScHARe
0 / 19 CDEs assigned

Tags
Topics tagged in this collection
Cross-Sectional Study State-Level Data

ScHARe

CDE Mapping: Option 1



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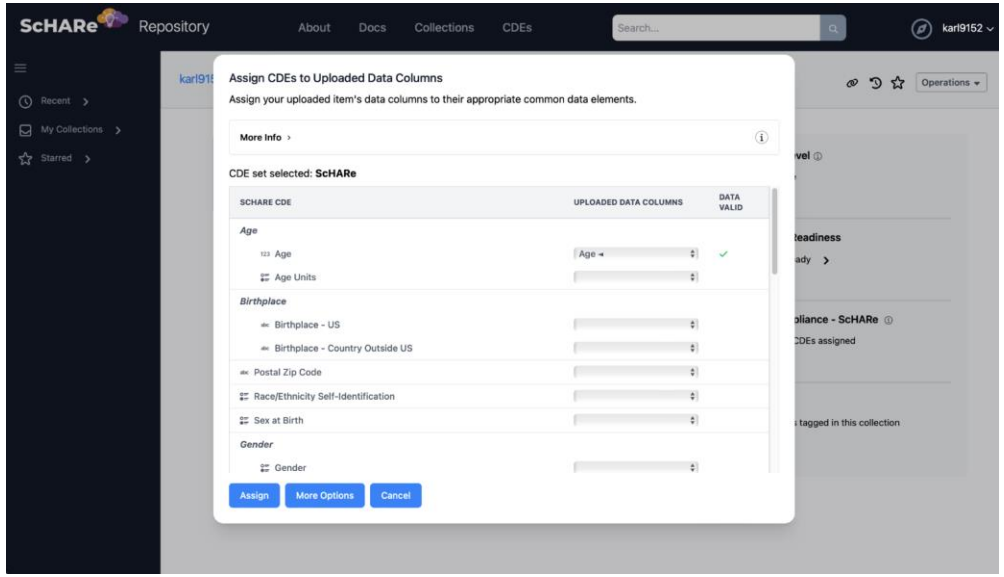
OF KNOWLEDGE GENERATION

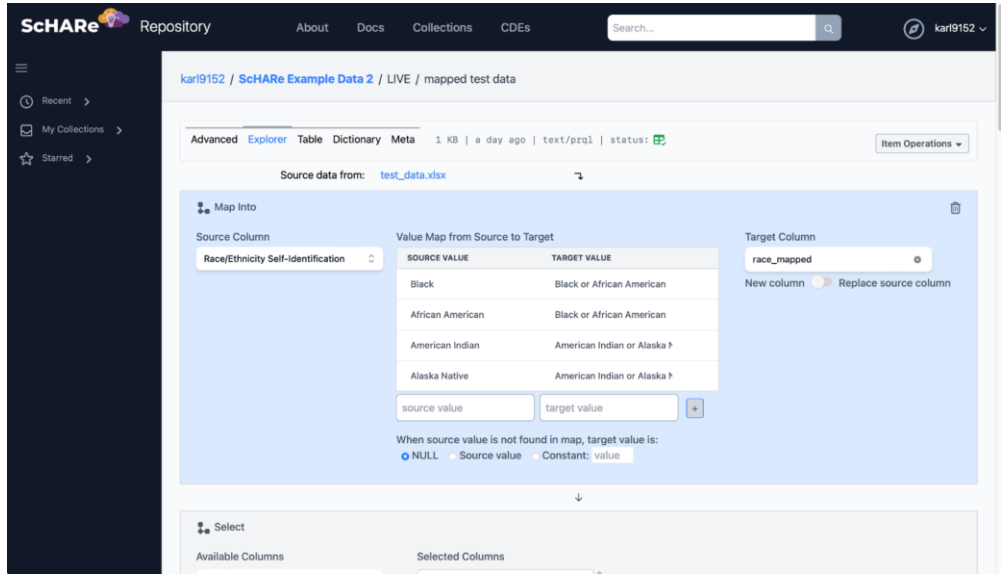
Getting Started with Mapping CDEs

- The Repository does not *enforce* CDEs, but it does *encourage* using CDEs
- Start with the data you have, and use the tools the repository offers to map as much of your data to CDEs as possible

Assign CDEs at Upload



Map CDEs using Dataviews



Assigning CDEs at Upload

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Don
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Links and Documents

Data Items

STATUS	NAME	SIZE
	example_data.csv	25 KB

Page 1 of 1

Drag and Drop or Browse Files to Upload

Metadata and Statistics

Match CDEs with column headings

The first step is to automatically detect alignments between your data and the ScHARe CDE set. Unless otherwise indicated, please select ScHARe below.

Select the CDEs you want to assign:

ScHARe (19 CDEs)

CDE matching method:

Using column headers

Next Cancel

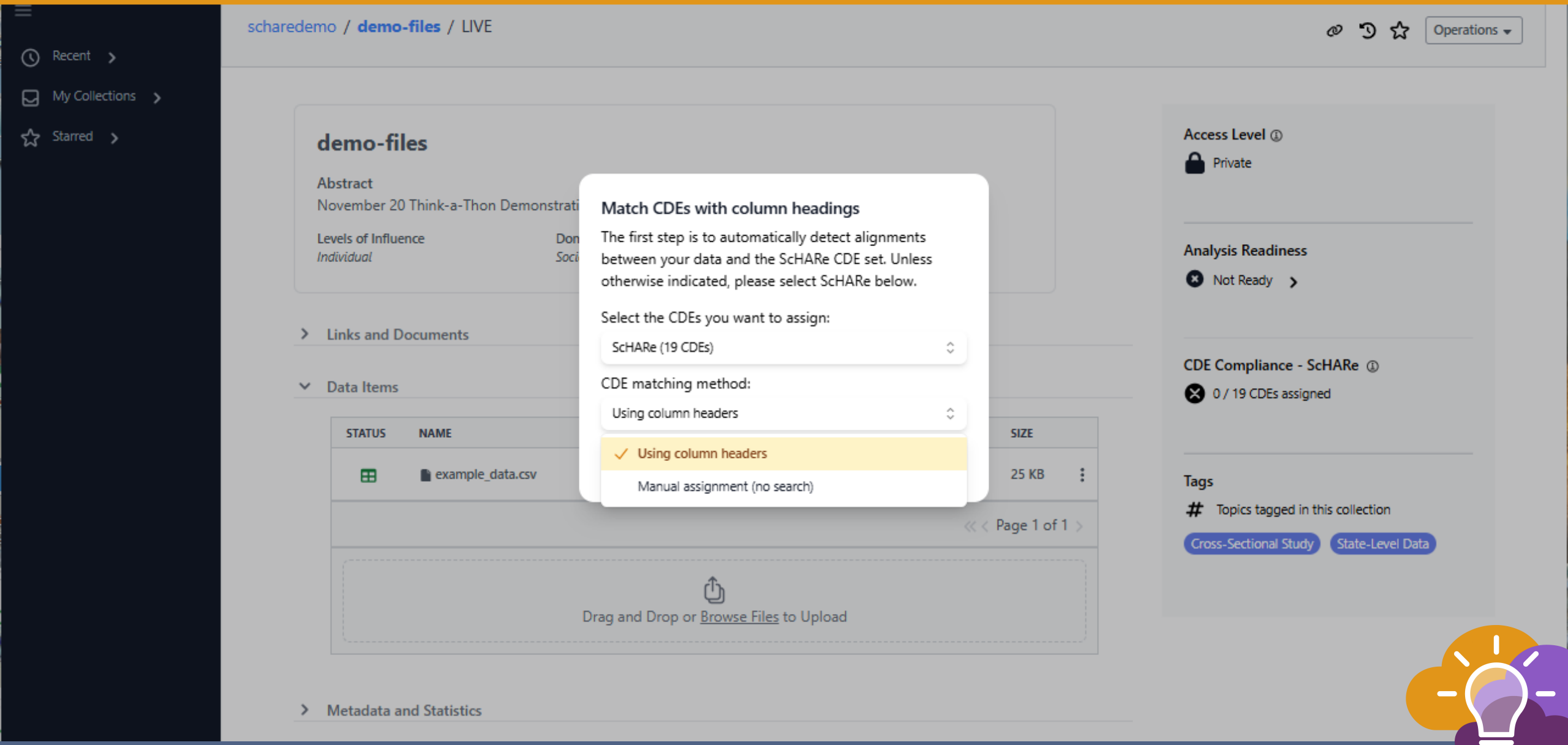
Access Level
Private

Analysis Readiness
Not Ready

CDE Compliance - ScHARe
0 / 19 CDEs assigned

Tags
Topics tagged in this collection
Cross-Sectional Study State-Level Data

Assigning CDEs at Upload



Assigning CDEs at Upload

Some of the assignments will be correct -- double-check the validation and the column name matches what you expect

Complete or cancel the process, or use "More Options" to go to a detailed tool for CDE assignment

Some of the assignments will be wrong or missing -- add anything that should be added, and double-check the validation

Assign CDEs to Uploaded Data Columns

Assign your uploaded item's data columns to their appropriate common data elements.

More Info ›

CDE set selected: **ScHARe**

SCHARE CDE	UPLOADED DATA COLUMNS	DATA VALID
Age		
Age	age	✓
Age Units	age_units	✓
Birthplace		
Birthplace - US		
Birthplace - Country Outside US		
Postal Zip Code	zip_code	✓
Race/Ethnicity Self-Identification	race_ethnicity_1	✗
Sex at Birth	sex_at_birth	✓
Gender		
Gender	gender	✗

Assign | More Options | Cancel

Assigning CDEs at Upload

Assign CDEs to Uploaded Data Columns

Assign your uploaded item's data columns to their appropriate common data elements.

More Info ›

CDE set selected: **ScHARe**

Postal Zip Code	zip_code	✓
Race/Ethnicity Self-Identification	race_ethnicity_1	✗
Sex at Birth		
Gender		
Gender		
Gender - Select Other		
Gender - Specify		
Sexual Orientation		
Sexual Orientation		
Sexual Orientation - Select Other		
Sexual Orientation - Specify		
Marital Status	marital_status	✓

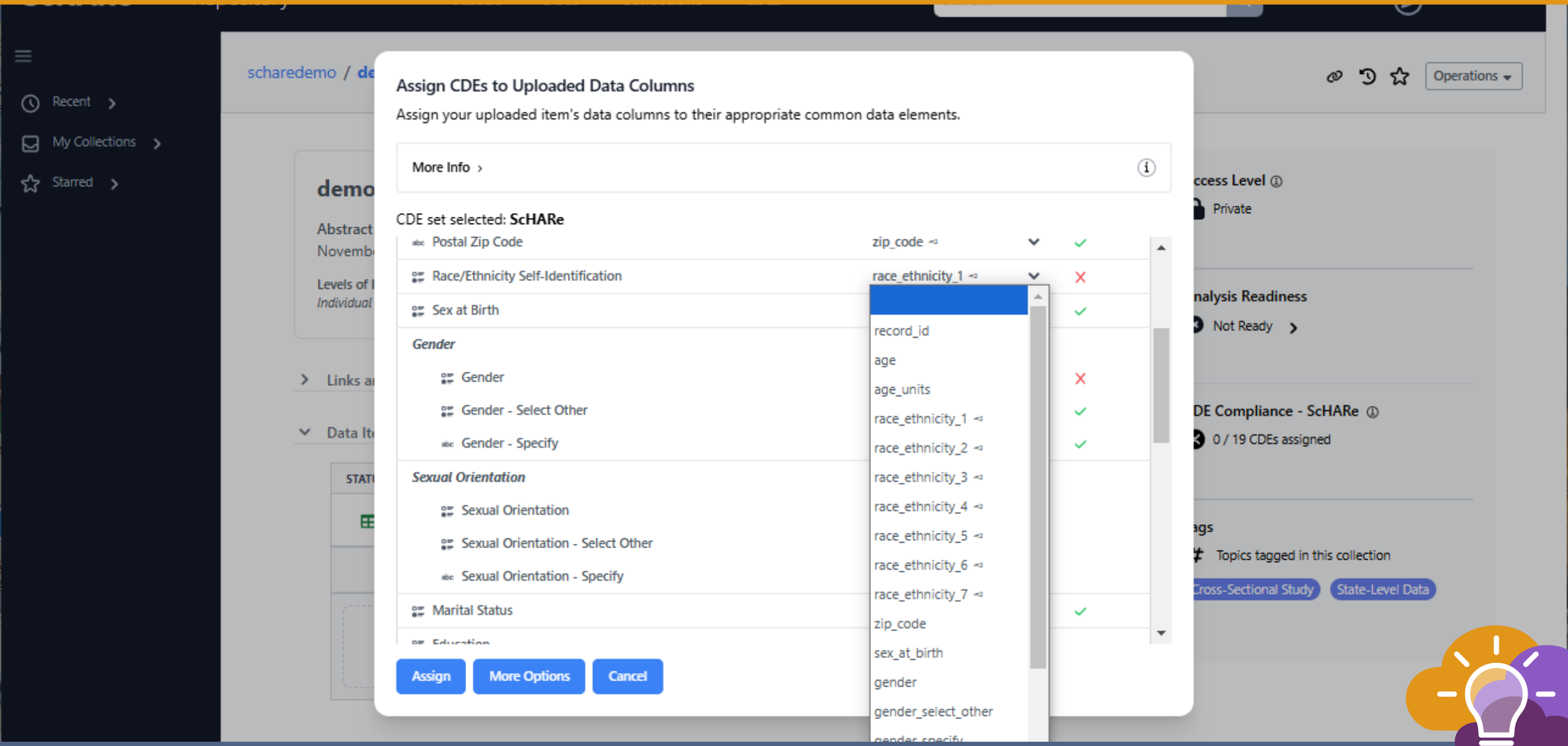
Row 1 "no" is not one of ["American Indian or Alaska Na
Row 2 "yes" is not one of ["American Indian or Alas...
Row 3 "no" is not one of ["American Indian or Alask...
Row 4 "no" is not one of ["American Indian or Alask...
Row 5 "yes" is not one of ["American Indian or Alas...
Row 6 "no" is not one of ["American Indian or Alask...
Row 7 "no" is not one of ["American Indian or Alask...
Row 8 "no" is not one of ["American Indian or Alask...
Row 9 "no" is not one of ["American Indian or Alask...
Row 10 "yes" is not one of ["American Indian or Ala...
Row 11 "no" is not one of ["American Indian or Alas...

Assign | More Options | Cancel

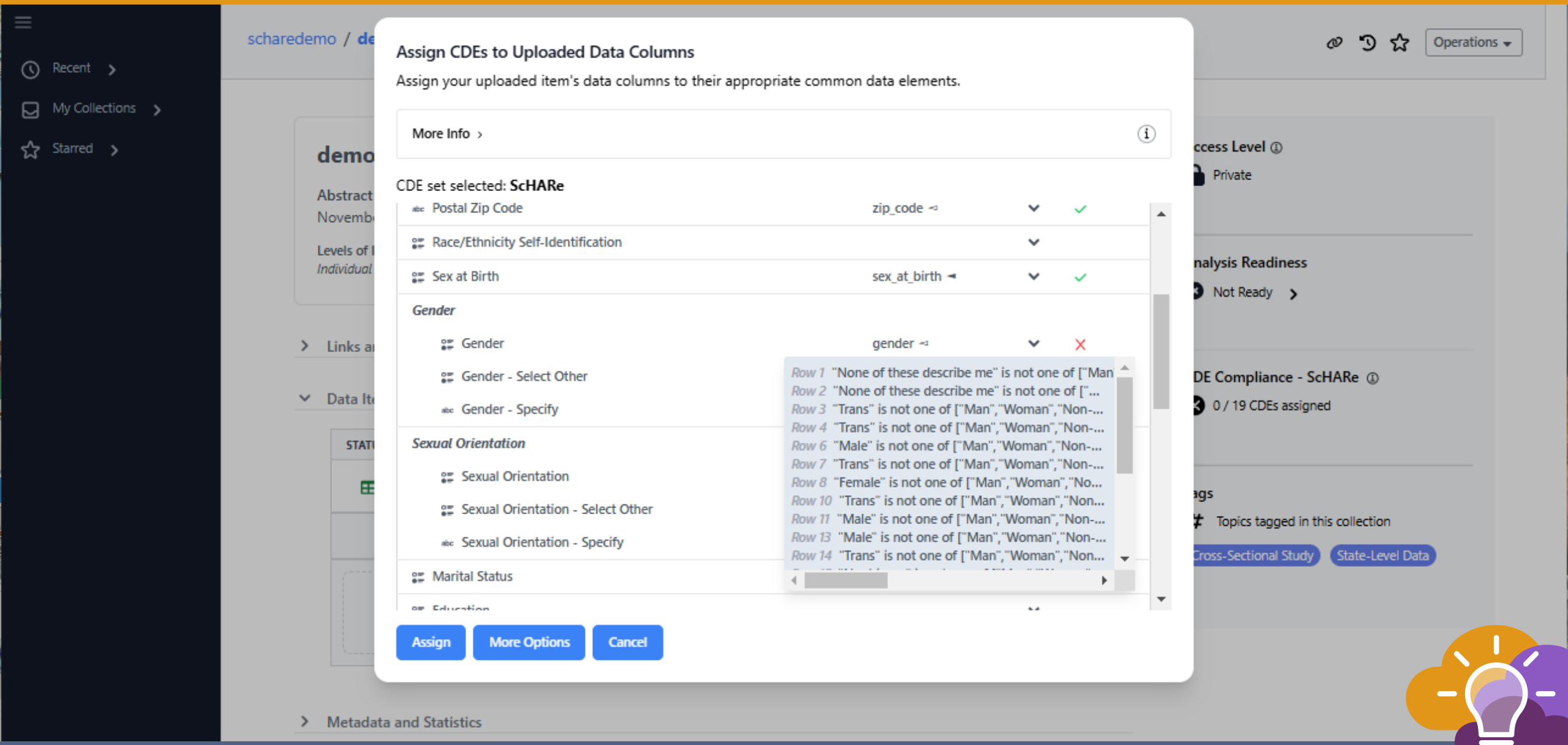
When an assigned CDE fails validation, hover over the red X to get details on why

NOTE: CDE validation errors can be corrected using dataviews (coming up later)

Assigning CDEs at Upload



Assigning CDEs at Upload



Assigning CDEs at Upload

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Abstract
Novemb

Levels of
Individual

Links a

Data It

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Metadata and Statistics

ccess Level
Private

nalysis Readiness
Not Ready

DE Compliance - ScHARe
0 / 19 CDEs assigned

ags
Topics tagged in this collection
Cross-Sectional Study
State-Level Data

Assign CDEs to Uploaded Data Columns

Assign your uploaded item's data columns to their appropriate common data elements.

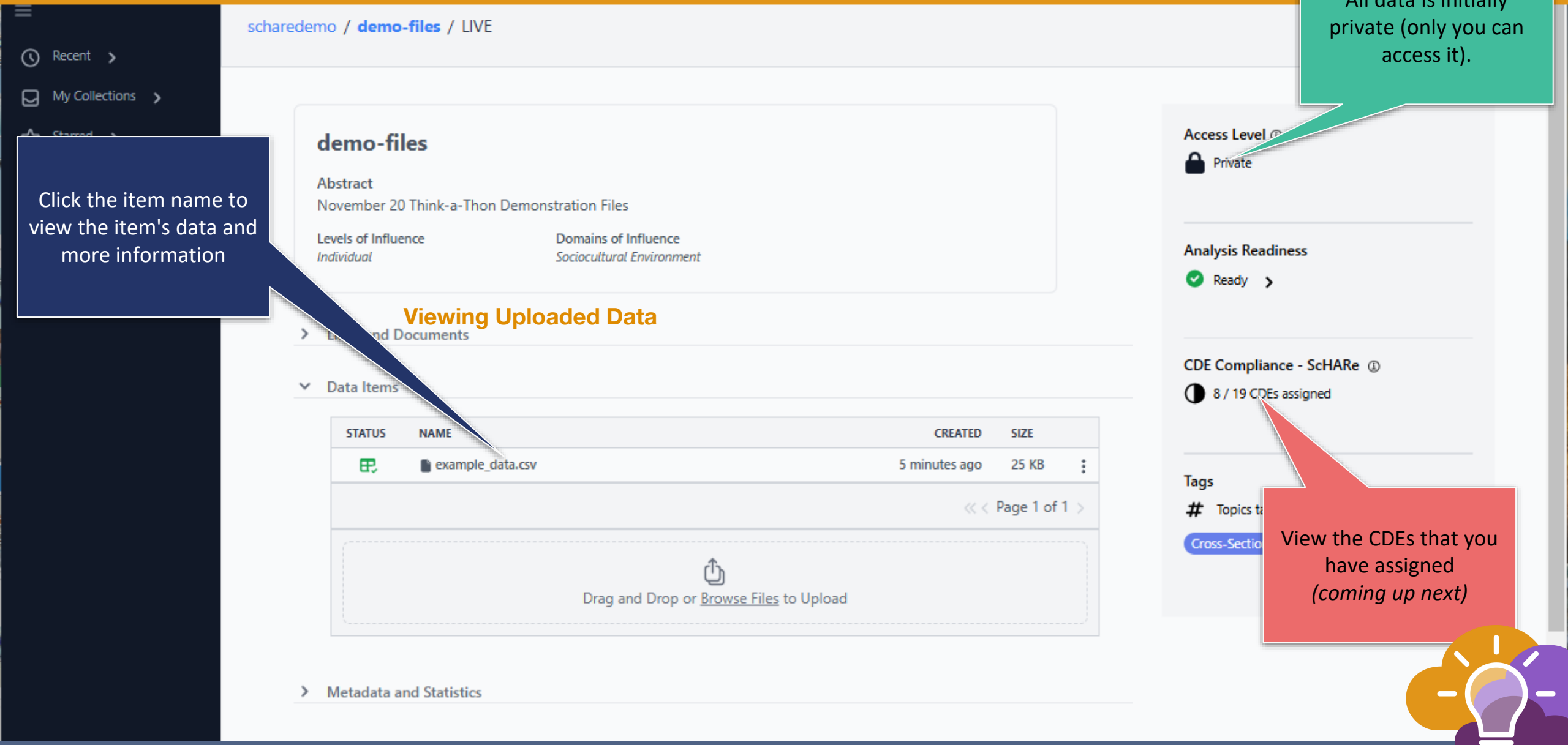
More Info ›

CDE set selected: **ScHARe**

Postal Zip Code	zip_code	✓
Race/Ethnicity Self-Identification		
Sex at Birth	sex_at_birth	✓
Gender		
Gender		
Gender - Select Other	gender_select_other	✓
Gender - Specify	gender_specify	✓
Sexual Orientation		
Sexual Orientation		
Sexual Orientation - Select Other		
Sexual Orientation - Specify		
Marital Status	marital_status	✓

Assign | More Options | Cancel

Viewing Uploaded Data



All data is initially private (only you can access it).

Click the item name to view the item's data and more information

View the CDEs that you have assigned *(coming up next)*

Viewing Uploaded Data

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Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	_data.csv	5 minutes ago	25 KB

Storage: ok
Parser: ok
Validator: ok

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Drag and Drop or Browse Files to Upload

Metadata and Statistics

Access Level
Private

Analysis Readiness
Ready

CDE Compliance - ScHARe
8 / 19 CDEs assigned

Tags
Topics tagged in this collection
Cross-Sectional Study
State-Level Data

The item status shows all good or any problems in storage, parsing, or validation

https://test-schare.nimhd.nih.gov/collections/e6d24c56-a0aa-4b89-b8f6-437245084a69/view/LIVE/example_data.csv?s=meta

Viewing Uploaded Data

Click the collection name to return to the collection main page

Recent
My Collections
Starred

scharedemo / **demo-files** / LIVE / example_data.csv

File Table Dictionary Meta 25 KB | 10 minutes ago | text/csv | status:

Item Operations

View the original file, the parsed data as a table, the item's data dictionary, and relevant metadata

For columns with CDEs assigned, click the info popup to view the CDE details

Perform operations on the data (download, rename, move, delete, etc.)

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
1943	92	Years	no	no	no	yes	no	no	no	28752	Male	None of these describe me
6688	76	Years	yes	no	no	no	no	no	no	10032		None of these describe me
9784	18	Years	no	no	yes	no	no	yes	no	07501		Trans
5193	91	Years				no	yes	no	no			Trans
8502	86	Years				no	no	no	no			Prefer not to answer
1210	72	Years				no	yes	no	no			Male
3563	79	Years				no	no	no	no			Trans
1172	46	Years	no	no	no	no	no	yes	no	37208	Prefer not to answer	Female
2618	80	Years	no	no	no	yes	no	no	no	35405	Male	Prefer not
6809	58	Years	yes	no	no	no	no	no	no	11769	None of the describe m	

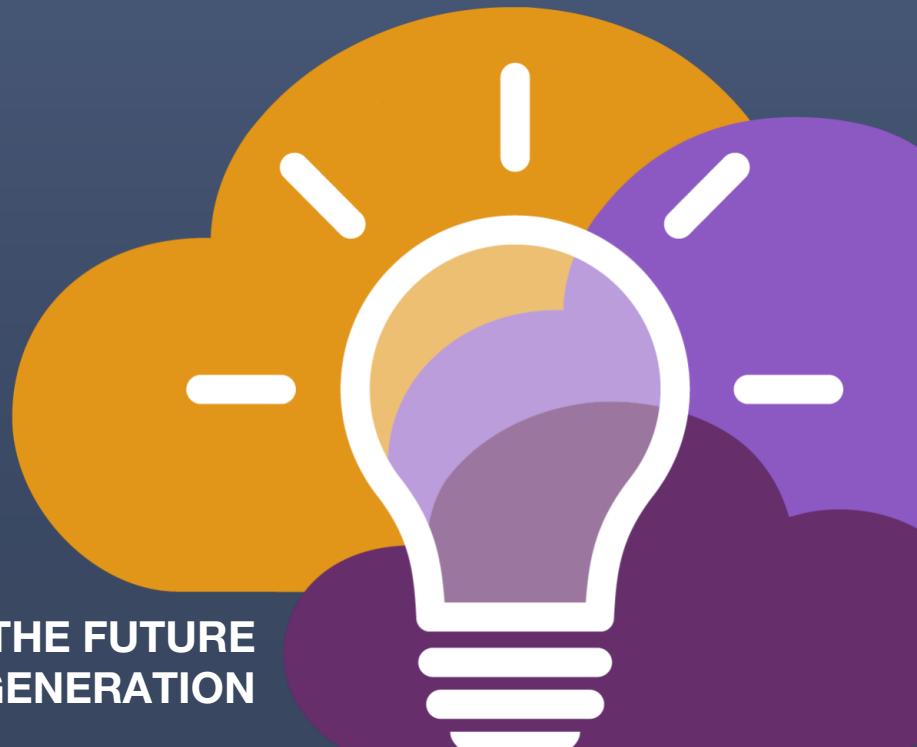
ScHARe Repository
Introduction

November 20, 2024

Deborah Duran, PhD · NIMHD
Elif Dede Yildirim, PhD · NIMHD
Mark Aronson, PhD · NIMHD

ScHARe

CDE Mapping



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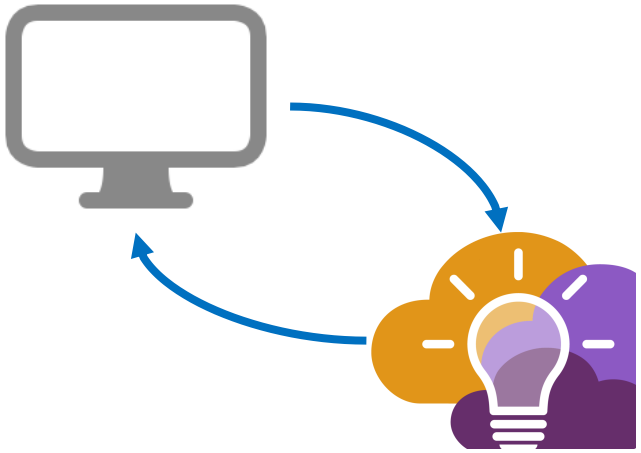
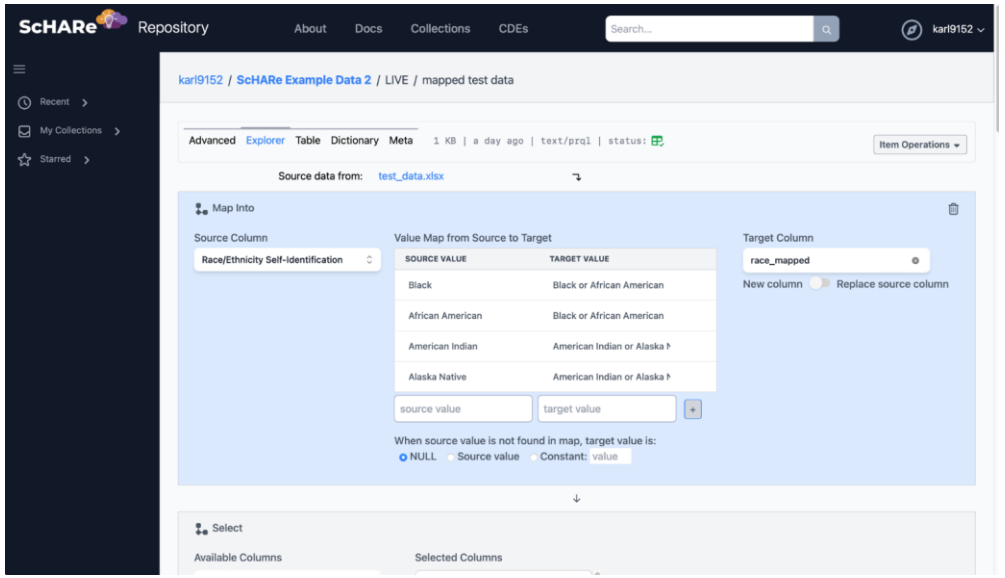
Using Dataviews to Map CDEs

If your data doesn't conform to the CDEs as it was uploaded, you have two options:

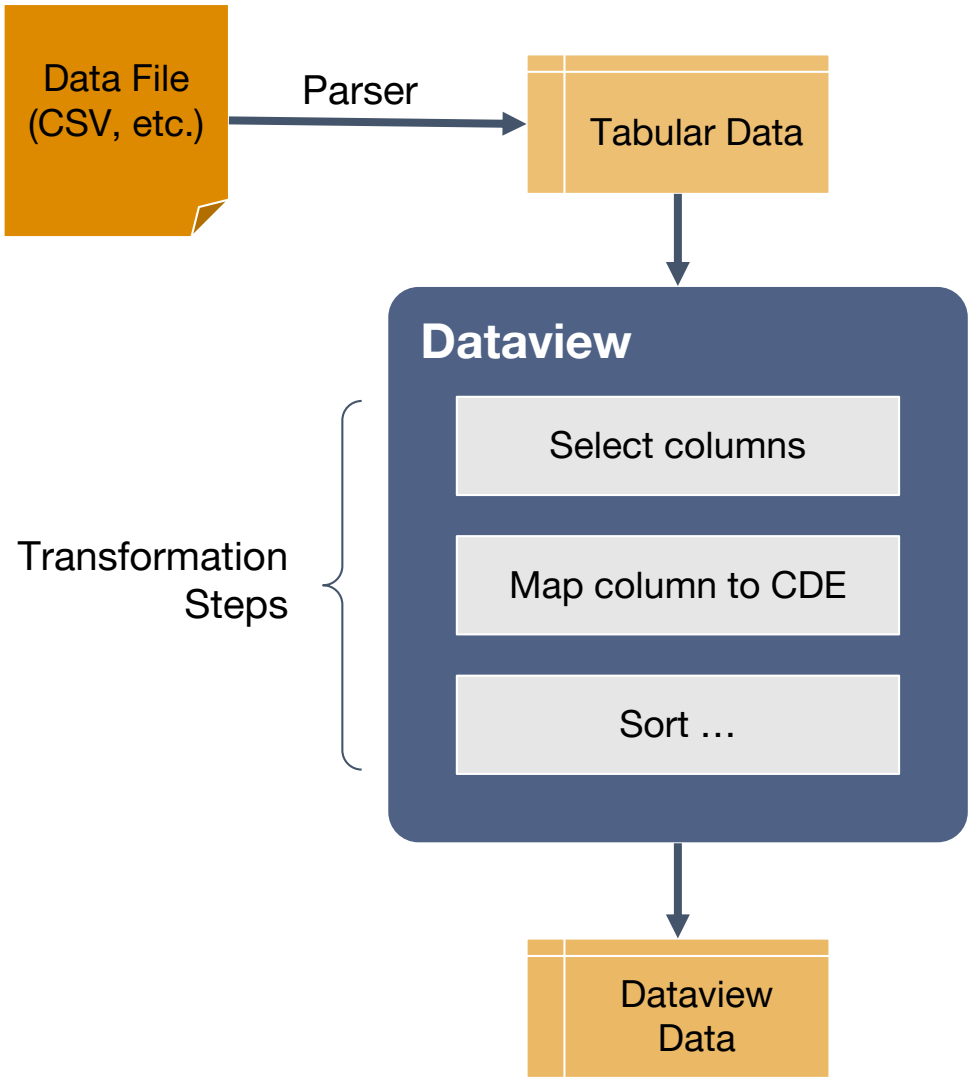
Use your own tools to adjust the data and re-upload



Use a Dataview to Map to CDEs within the Repository



What is a Dataview?



Dataviews take data from one or more sources, apply a series of transformation steps to that data *(filtering, sorting, mapping, etc.)* resulting in a new table of data as output.

Uses of Dataviews:

- Creating subsets of data
- Hiding PHI/PII for publishing
- Summarizing individual-level data into subsets and estimates
- Joining multiple datasets together
- **Mapping to CDEs**
- … many others!

Mapping CDEs via Dataview

ScHARe Repository

About Docs Collections CDEs

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scharedemo

Recent

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scharedemo / **demo-files** / LIVE / example_data.csv

File Table Dictionary Meta

25 KB | an hour ago | text/csv | status:

Item Operations

- Rename...
- Copy To...
- Link To...
- Move To Folder...
- Configure Table
- Assign Data Dictionary...
- Create Dataview...
- Import as REDCap Data Dictionary
- Export Table Data...
- Download
- Delete

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_cod	
1943	92	Years	no	no	no	yes	no	no	no	28752	
6688	76	Years	yes	no	no	no	no	no	no	10032	
9784	18	Years	no	no	yes	no	no	yes	no	07501	
5193	91	Years	no	no	no	no	yes	no	no	26726	
8502	86	Years	yes	no	no	no	no	no	no	99737	
1210	72	Years	no	no	no	no	yes	no	no	52223	
3563	79	Years	no	yes	no	no	no	no	no	53186	
1172	46	Years	no	no	no	no	no	yes	no	37208	
2618	80	Years	no	no	no	yes	no	no	no	35405	Male

Step 1: Create a new Dataview

Recent
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scharedemo / **demo-files** / LIVE / example_data.csv

File Table Dictionary Meta 25 KB | 10 minutes ago | text/csv | status:

Item Operations

Item Info

Item ID	fb06dec8-0ac2-4c6d-ad62-b4adf5f3277c
Item Type	file
Name	example_data.csv
Folder ID	ROOT
Created on	2024-11-20T01:35:00
Item URL	pigeon://test-schare.nimhd.nih.gov/e6d24c56-a0aa-4b89-b8f6-437245084a69/LIVE/fb06dec8-0ac2-4c6d-ad62-b4adf5f3277c

Metadata

KEY	VALUE
content-type	text/csv
Content-type	text/csv

Storage

URL	pigeon+datastore://pigeon_s3/360a562b-e312-474e-abcd-d944da509425
Size	25994 bytes
Checksum	{ "sha-256": "dSjkNHqi7UweXRJRBOb0ALMkXrqFIfo3m8C4nU7hKIU=" }

Create Dataview

Dataview name

Create Dataview Cancel

Step 1: Create a new Dataview

Recent
My Collections
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scharedemo / **demo-files** / LIVE / example_data.csv

File Table Dictionary Meta 25 KB | 10 minutes ago | text/csv | status:

Item Operations

Item Info

Item ID	fb06dec8-0ac2-4c6d-ad62-b4adf5f3277c
Item Type	file
Name	example_data.csv
Folder ID	ROOT
Created on	2024-11-20T01:35:00
Item URL	pigeon://test-schare.nimhd.nih.gov/e6d24c56-a0aa-4b89-b8f6-437245084a69/LIVE/fb06dec8-0ac2-4c6d-ad62-b4adf5f3277c

Metadata

KEY	VALUE
content-type	text/csv
Content-type	text/csv

Storage

URL	pigeon+datastore://pigeon_s3/360a562b-e312-474e-abcd-d944da509425
Size	25994 bytes
Checksum	{ "sha-256": "dSjkNHqi7UweXRJRBOb0ALMkXrqFIfo3m8C4nU7hKIU=" }

Create Dataview

example-dataview

Create Dataview Cancel

Step 2: Add Mapping Steps to your Dataview

Recent
My Collections
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scharedemo / **demo-files** / LIVE / example-dataview

Advanced Explorer Table Dictionary Meta 559 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example_data.csv

Take

Number of rows Range of rows Limit output to Number of Rows

10

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Results › Data available 0 parsing errors 0 validation errors

Transformation Preview

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
1943	92	Years	no	no	no	yes	no	no	no	28752	Male	None of these
6688	76	Years	yes	no	no	no	no	no	no	10032	Male	
0784	18	Years	no	no	yes	no	no	yes	no	07501	Male	

Step 2: Add Mapping Steps to your Dataview

Recent
My Collections
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scharedemo / **demo-files** / LIVE / example-dataview

Advanced Explorer Table Dictionary Meta 559 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example_data.csv

Take

Number of rows Range of rows Limit output to Number of Rows

10

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Select Columns
Filter Rows
Sort
Shuffle
Join
Take Rows
Rename Column
Map Column
Aggregate Rows

Data available 0 parsing errors 0 validation errors

on Preview

age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
Years	no	no	no	yes	no	no	no	28752	Male	None of these
Years	yes	no	no	no	no	no	no	10032	Male	

Step 2: Add Mapping Steps to your Dataview

Recent
My Collections
Starred

scharedemo / **demo-files** / LIVE / example-dataview

Advanced Explorer Table Dictionary Meta 559 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example_data.csv

Take

Number of rows Range of rows Limit output to Number of Rows

10

Map Into

Source Column

Select column...

* Column selection is required

Value Map from Source to Target

source value target value +

* At least one map entry is required

When source value is not found in map, target value is:

NULL Source value Constant: value

Target Column

new column name

New column Replace source column

* Target Column is required

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview

Step 2: Add Mapping Steps to your Dataview

Map Into

Source Column

gender

Value Map from Source to Target

SOURCE VALUE	TARGET VALUE
Male	Man

source value | target value | +

When source value is not found in map, target value is:

NULL Source value Constant: value

Target Column

gender_mapped

New column Replace source column

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Results › Data available 0 parsing errors 0 validation errors

Transformation Preview

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
1210	72	Years	no	no	no	no	yes	no	no	52223	Female	Male
1943	92	Years	no	no	no	yes	no	no	no	28752	Male	None of
6688	76	Years	yes	no	no	no	no	no	no	10032	Male	

Step 2: Add Mapping Steps to your Dataview

Map Into

Source Column

gender

Value Map from Source to Target

SOURCE VALUE	TARGET VALUE
Male	Man
Female	Woman
Trans	Transgender
Nonbinary	Non-Binary
None of these describe me	None of these describe me

source value | target value | +

When source value is not found in map, target value is:

NULL Source value Constant: value

Target Column

gender_mapped

New column Replace source column

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Results › Data available 0 parsing errors 0 validation errors

Transformation Preview

Step 3: Assign CDEs to Data Columns

Map Into

Source Column

gender

ce source column

Add Data Elements

You can enhance your dataview by adding new data elements or modifying existing ones that were derived from its source data.

COLUMN	DATA ELEMENT	REPRESENTS PV
age	*Age*	*N/A*
age_units	*Age Units*	*N/A*
zip_code	*Postal Zip Code*	*N/A*
sex_at_birth	*Sex at Birth*	*N/A*
gender_select_other	*Gender - Select Other*	*N/A*

Add new data element annotation:

Select a column...

Add

From: CDEs | Data Dictionary

Select a data element...

Clear

CDE set selected: **ScHARe**

Done

+ Add Step

Clear Dataview

Save Dataview

Results ›

✓ Data available

✓ 0 parsing errors

✓ 0 validation errors

Transformation Preview

Step 3: Assign CDEs to Data Columns

Map Into

Source Column

gender

Add Data Elements

You can enhance your dataview by adding new data elements or modifying existing ones that were derived from its source data.

COLUMN	DATA ELEMENT	REPRESENTS PV
age	*Age*	*N/A*
age_units	*Age Units*	*N/A*
zip_code	*Postal Zip Code*	*N/A*
sex_at_birth	*Sex at Birth*	*N/A*
gender_select_other	*Gender - Select Other*	*N/A*

Add new data element annotation: gender_mapped

Add

From: CDEs | Data Dictionary

Gender

Clear

CDE set selected: **ScHARe**

OPTIONAL: Select a PV...

Done

+ Add Step

Clear Dataview

Save Dataview

Results ›

✓ Data available

✓ 0 parsing errors

✓ 0 validation errors

Transformation Preview

Step 3: Assign CDEs to Data Columns

Results ✓ Data available ✓ 0 parsing errors ✓ 0 validation errors

No errors to report!

Transformation Preview

y	measure_0	measure_1	measure_2	measure_3	measure_4	measure_5	measure_6	measure_7	measure_8	measure_9	gender_mapped
	62	0.5455549357622266	1	0.5884900154230546	0.12911211858353722	57	33	0.7170385313006806	0.8788787389282339	0.5467863499436898	None of these describe me. I would like to consider additional options
	90	0.9939486148968586	18	0.8889859573142674	0.9745095524972497	2	68	0.7794942573077963	0.34939465386130986	0.2571283059006645	None of these describe me. I would like to consider additional options
	92	0.1187476169408952	1	0.6512384712588953	0.8971788616590552	57	15	0.5303711405755923	0.45273835850696076	0.4082502293654543	Transgender
	60	0.4452622773910989	10	0.5971200227987504	0.7493012469195882	98	92	0.8712062558952113	0.4832045355262965	0.9295209737850779	Transgender
	53	0.971610341237526	55	0.8817829051636139	0.05976090957174052	77	88	0.5610231545798023	0.6188743418431822	0.8298724376862494	Man
	15	0.6678690757541459	12	0.35150592643125234	0.016162277012149118	98	24	0.4741302934986361	0.3494528319110445	0.5733822336463569	Transgender
	93	0.20797803936217862	88	0.5164279582660238	0.17957863745725022	18	6	0.3757660830284647	0.6016044994045969	0.35718866008810335	Woman
	49	0.33569642444900216	25	0.8284451772569406	0.1251105503540758	92	56	0.7920621573885018	0.46157047423521724	0.5849628410398715	Transgender
	55	0.4669418786022268	59	0.9681471694553496	0.1829245483682186	38	69	0.16838001266365477	0.654926782920557	0.4987917893025189	
	34	0.31022787630950976	53	0.2198646710684642	0.024882302497037267	87	99	0.38764603267169684	0.7459103083590588	0.9586660722941287	

rows per page: 25 1–10 of

Step 3: Assign CDEs to Data Columns

Source Column

gender

Value Map from Source to Target

SOURCE VALUE	TARGET VALUE
Male	Man

Target Column

gender_mapped

New column Replace source column

Add Data Elements

You can enhance your dataview by adding new data elements or modifying existing ones that were derived from its source data.

COLUMN	DATA ELEMENT	REPRESENTS PV
gender_mapped	Gender	*N/A*
age	*Age*	*N/A*
age_units	*Age Units*	*N/A*
zip_code	*Postal Zip Code*	*N/A*
sex_at_birth	*Sex at Birth*	*N/A*

Add new data element annotation:

Select a column...

Add

From: CDEs Data Dictionary

Select a data element...

Clear

CDE set selected: ScHARe

Done

+ Add Step

Clear Dataview Save Dataview

Results

✓ 0 validation errors

No errors to report

Transformation Preview

iency	measure_0	measure_1	measure_2	measure_3	measure_4	measure_5	measure_6	measure_7	measure_8	measure_9	gen
	62	0.5455549357622266	1	0.5884900154230546	0.12911211858353722	57	33	0.7170385313006806	0.8788787389282339	0.5467863499436898	

Step 3: Assign CDEs to Data Columns

Source Column

gender

Value Map from Source to Target

SOURCE VALUE	TARGET VALUE

Target Column

gender_mapped

ce source column

Add Data Elements

You can enhance your dataview by adding new data elements or modifying existing ones that were derived from its source data.

COLUMN	DATA ELEMENT	REPRESENTS PV
gender_mapped	Gender	*N/A*
age	*Age*	*N/A*
age_units	*Age Units*	*N/A*
zip_code	*Postal Zip Code*	*N/A*
sex_at_birth	*Sex at Birth*	*N/A*

Add new data element annotation:

From: CDEs | Data Dictionary

race_ethnicity_1

Race/Ethnicity Self-Identification

CDE set selected: ScHARe

American Indian or Alaska Native

Add

Clear

Done

+ Add Step

Clear Dataview

Save Dataview

Results

0 validation errors

No errors to report

Transformation Preview

iency	measure_0	measure_1	measure_2	measure_3	measure_4	measure_5	measure_6	measure_7	measure_8	measure_9	gen
	62	0.5455549357622266	1	0.5884900154230546	0.12911211858353722	57	33	0.7170385313006806	0.8788787389282339	0.5467863499436898	

Step 3: Assign CDEs to Data Columns

Source Column

gender

Value Map from Source to Target

SOURCE VALUE	TARGET VALUE
Male	Man

Target Column

gender_mapped

New column Replace source column

Add Data Elements

You can enhance your dataview by adding new data elements or modifying existing ones that were derived from its source data.

COLUMN	DATA ELEMENT	REPRESENTS PV
gender_mapped	Gender	*N/A*
race_ethnicity_1	Race/Ethnicity Self-Identification	American Indian or Alaska Native
age	*Age*	*N/A*
age_units	*Age Units*	*N/A*
zip_code	*Postal Zip Code*	*N/A*

Add new data element annotation:

From: CDEs Data Dictionary

Select a column...

Select a data element...

CDE set selected: **ScHARe**

Add

Clear

Done

+ Add Step

Clear Dataview Save Dataview

Results

✓ 0 validation errors

No errors to report

Transformation Preview

ficiency	measure_0	measure_1	measure_2	measure_3	measure_4	measure_5	measure_6	measure_7	measure_8	measure_9	g
	62	0.5455549357622266	1	0.5884900154230546	0.12911211858353722	57	33	0.7170385313006806	0.8788787389282339	0.546786349943689	

Step 3: Assign CDEs to Data Columns

+ Add Step | Libraries: | Add Library | Add Data Elements | Clear Dataview | Save Dataview

Results | Data available | 0 parsing errors | 0 validation errors

No errors to report!

Transformation Preview

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
1943	92	Years	no					no	no	28752	Male	None of these describe me
6688	76	Years	yes					no	no	10032	Male	None of these describe me
9784	18	Years	no					yes	no	07501	Male	Trans
5193	91	Years	no					no	no	26726	None of these describe me	Trans
1210	72	Years	no					no	no	52223	Female	Male
3563	79	Years	no					no	no	53186	None of these describe me	Trans
1172	46	Years	no	no	no	no	no	yes	no	37208	Prefer not to answer	
6809	58	Years	yes	no	no	no	no	no	no	11769	None of	
8502	86	Years	yes	no	no	no	no	no	no	99737	Prefer not to	

Race/Ethnicity Self-Identification : American Indian or Alaska Native (string)

Concepts

C41259: American Indian or Alaska Native	*valueDomain*
C17049: Race	*dataElement*
C16564: Ethnic Group	*dataElement*
C74528: Self-Report	*dataElement*

Definitions ›

Step 3: Assign CDEs to Data Columns

Trans	Transgender

+ Add Step

Clear Dataview | Save Dataview

Add Data Elements

You can enhance your dataview by adding new data elements or modifying existing ones that were derived from its source data.

race_ethnicity_2	Race/Ethnicity Self-Identification	Asian or Asian American
race_ethnicity_3	Race/Ethnicity Self-Identification	Black or African American
race_ethnicity_4	Race/Ethnicity Self-Identification	Hispanic, Latino, or Spanish
race_ethnicity_5	Race/Ethnicity Self-Identification	Native Hawaiian or Other Pacific Islander
race_ethnicity_6	Race/Ethnicity Self-Identification	Middle Eastern or North African
race_ethnicity_7	Race/Ethnicity Self-Identification	White

Add new data element annotation:

Select a column...

Add

From: CDEs | Data Dictionary

Select a data element...

Clear

CDE set selected: ScHARe

Done

Results

✓ 0 validation errors

No errors to report

Transformation

record_id	age								race_ethnicity_7	zip_code	sex_at_birth
1943	92								no	28752	Male
6688	76	Years	yes	no	no	no	no	no	no	10032	
9784	18	Years	no	no	yes	no	no	yes	no	07501	
5193	91	Years	no	no	no	no	yes	no	no	26726	

Step 3: Assign CDEs to Data Columns

Results ✓ Data available ✓ 0 parsing errors ✓ 0 validation errors

No errors to report!

Transformation Preview

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth
1943	92	Years	no	no					no	28752	Male
6688	76	Years	yes	no					no	10032	Male
9784	18	Years	no	no					no	07501	Male
5193	91	Years	no	no					no	26726	None of thes describe me
1210	72	Years	no	no					no	52223	Female
3563	79	Years	no	yes					no	53186	None of thes describe me
1172	46	Years	no	no	no	no	no	yes	no	37208	Prefer not to answer
6809	58	Years	yes	no	no	no	no	no	no	11769	None of thes describe me
8502	86	Years	yes	no	no	no	no	no	no	99737	Prefer not to answer
2618	80	Years	no	no	no	yes	no	no	no	35405	

Race/Ethnicity Self-Identification : Asian or Asian American
(string)

Concepts

C41260: Asian or Asian American	*valueDomain*
C17049: Race	*dataElement*
C16564: Ethnic Group	*dataElement*
C74528: Self-Report	*dataElement*

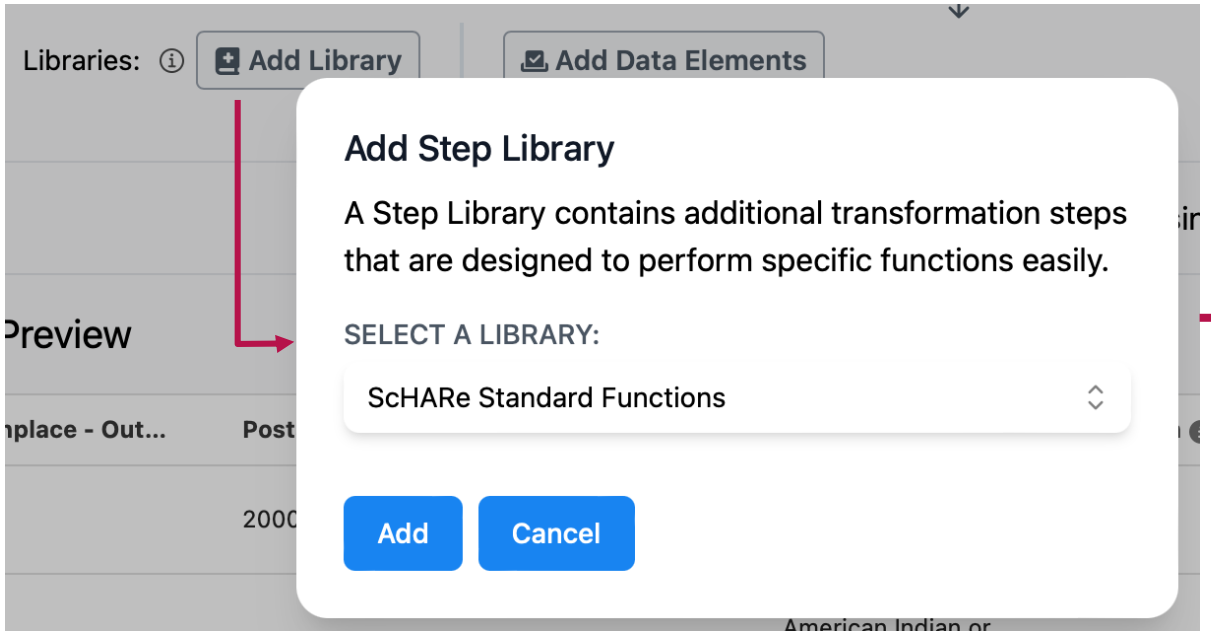
Definitions ›

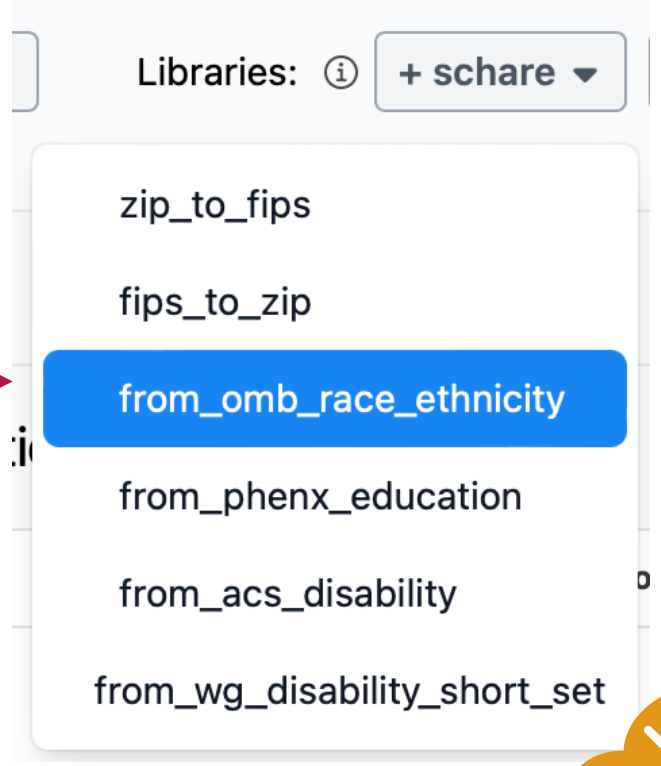
rows per page: 25 1–10 of

Mapping CDEs via Dataview

The system also has a number of specific mapping functions available, for cases when the mapping is standardized or when the mapping is more complex than can be handled by the generic mapping functions.

Please contact our support team if you need any help with custom mapping functions!





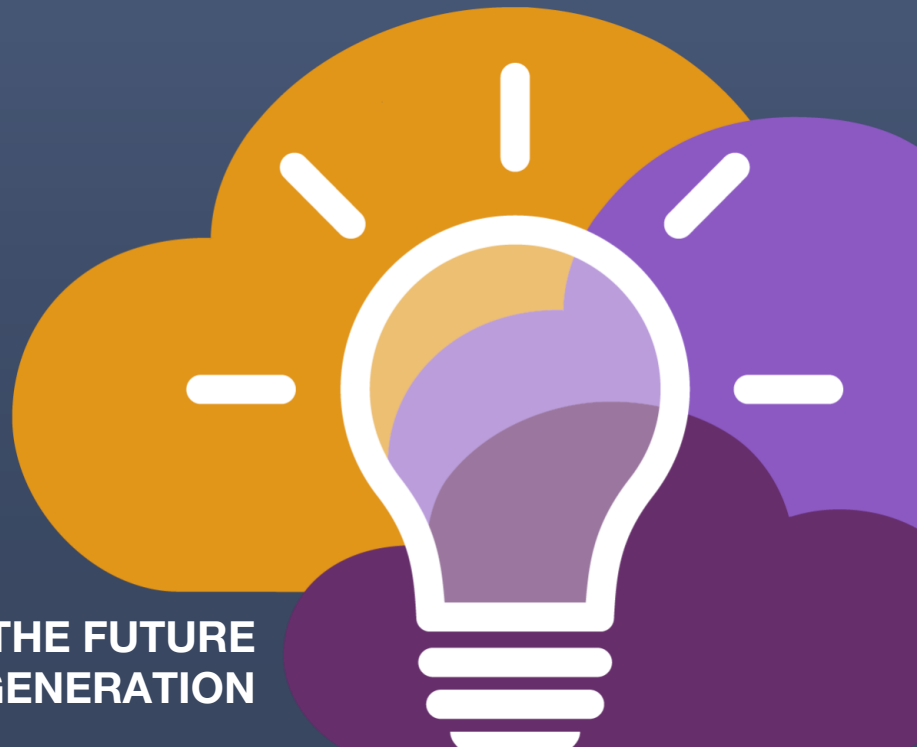
Slido Poll

What conditions would make you more likely to share your data publicly?

a) Proper anonymization and privacy safeguards
b) Clear contribution to scientific advancement
c) Personal or community benefit
d) Legal and ethical assurances
e) I wouldn’t share it under any circumstances

ScHARe

Sharing Data



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Viewing your Collection

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Operations

demo-files

Abstract
November 20 Think-a-Thon Demonstration Files

Levels of Influence
Individual

Domains of Influence
Sociocultural Environment

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	example_data.csv	34 minutes ago	25 KB
	example-dataview	20 minutes ago	2 KB

Page 1 of 1

Drag and Drop or Browse Files to Upload

Access Level
Private

Analysis Readiness
Ready

CDE Compliance - ScHARe
9 / 19 CDEs assigned

Tags
Topics tagged i
Cross-Sectional Stu

See whether your data is well-annotated or what you should improve

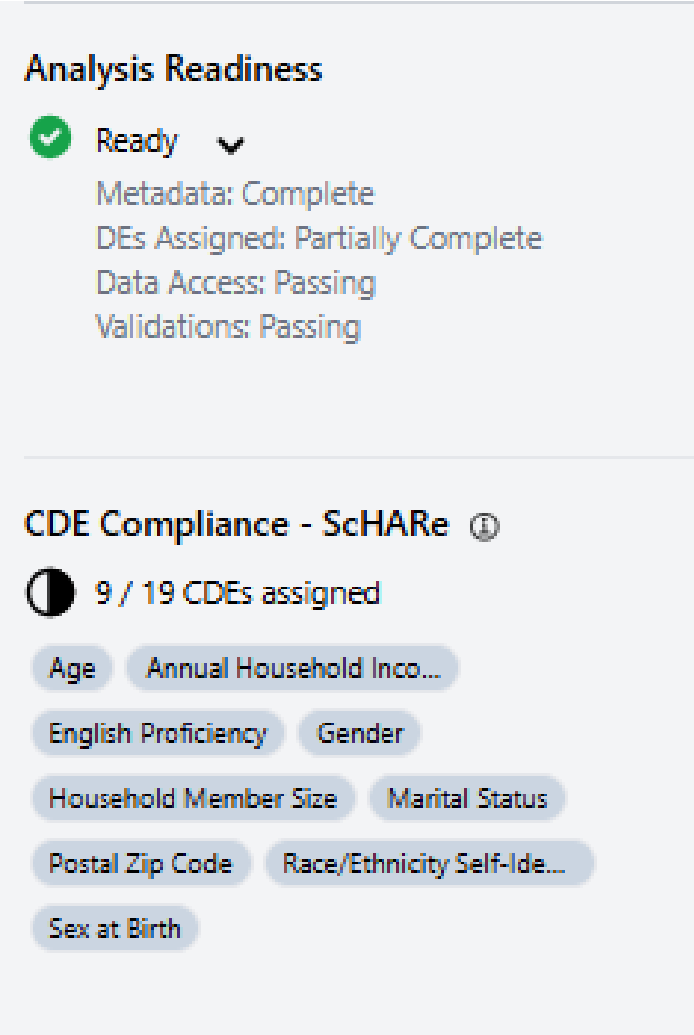
The item status shows all good or any problems in storage, parsing, or validation

View the CDEs that you have assigned

CDE Compliance and Analysis Readiness

Analysis Readiness - a simple metric on whether your data is ready for downstream use

1. Did you assign **metadata** to your collection (tags, project-level CDEs)?
2. Have you partially or fully **assigned CDEs** to your data?
3. Is the data **accessible** to the system (no broken links)?
4. Does the data pass **validation** according to the assigned CDEs?



CDE Compliance - Showing how many CDEs have been assigned across the data in the collection

- Click on the metric to pop up the list of CDEs assigned
- Click on an individual CDE to find more information about that CDE

Access Levels and Sharing Data

Recent
My Collections
Starred

scharedemo / **demo-files** / LIVE

Operations

- Configure CDEs
- Add Readme
- Add Dictionary...
- Add Folder...
- Add Link...
- Make Private
- Share...
- Make Public
- Edit
- Delete Collection

demo-files

Abstract
November 20 Think-a-Thon Demonstration Files

Levels of Influence	Domains of Influence
Individual	*Sociocultural Environment*

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	example_data.csv	34 minutes ago	25 KB
	example-dataview	20 minutes ago	2 KB

Page 1 of 1

Drag and Drop or Browse Files to Upload

Metadata and Statistics

Access Level
Private

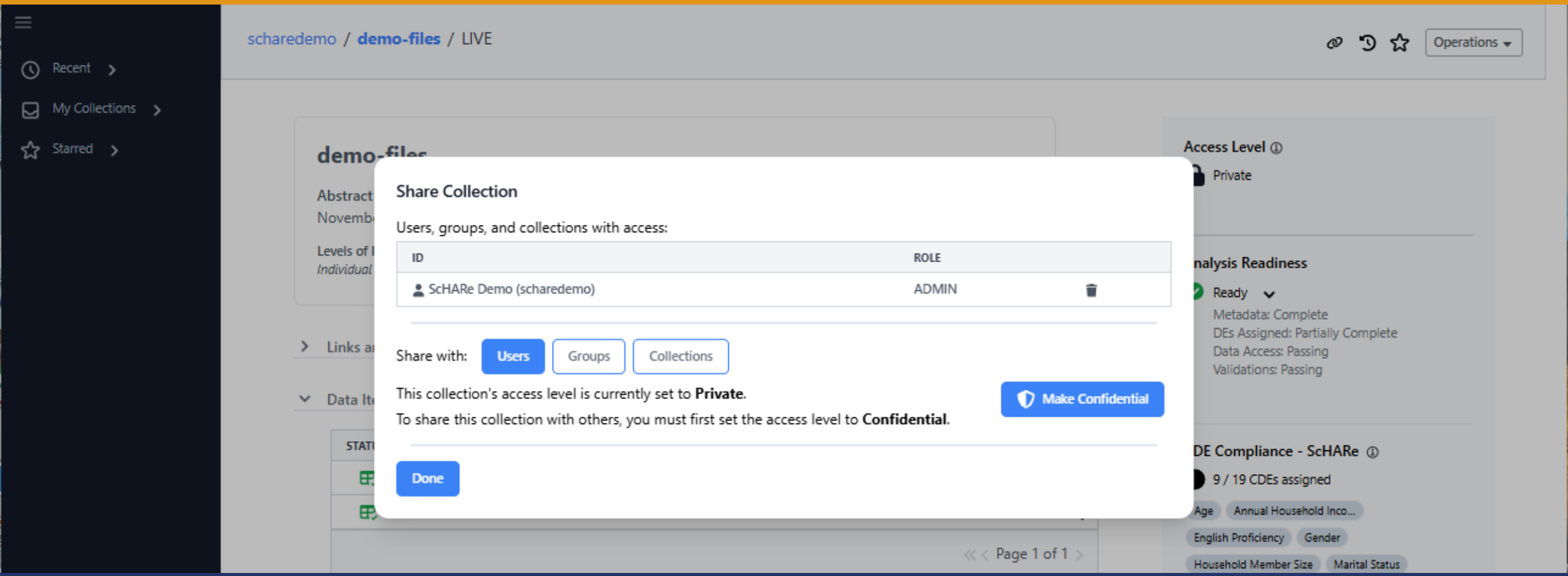
Analysis Readiness
Ready
Metadata: Complet
DEs Assigned: Parti
Data Access: Passin
Validations: Passing

CDE Compliance - ScHARe
9 / 19 CDEs assigned

Age | Annual Household Inco... | English Proficiency | Gender | Household Member Size | Marital Status | Postal Zip Code | Race/Ethnicity Self-Ide... | Sex at Birth

Tags
Topics tagged in this collection

Access Levels and Sharing Data



You have control over how your data is shared on the ScHARe Repository. By default, all collections start out as **Private**.

Access Levels and Sharing Data

ScHARe Repository

About Docs Collections CDEs

Search...

scharedemo

Collection authorization successfully updated.

Recent

My Collections

Starred

scharedemo / demo-files / LIVE

Operations

demo-files

Abstract

Novemb

Levels of I

Individual

Links a

Data It

STAT

Page 1 of 1

Drag and Drop or Browse Files to Upload

Access Level

Confidential

nalysis Readiness

Ready

Metadata: Complete

DEs Assigned: Partially Complete

Data Access: Passing

Validations: Passing

DE Compliance - ScHARe

9 / 19 CDEs assigned

Age | Annual Household Inco... | English Proficiency | Gender | Household Member Size | Marital Status | Postal Zip Code | Race/Ethnicity Self-Ide... | Sex at Birth

Share Collection

Users, groups, and collections with access:

ID	ROLE
ScHARe Demo (scharedemo)	ADMIN

Share with: Users | Groups | Collections

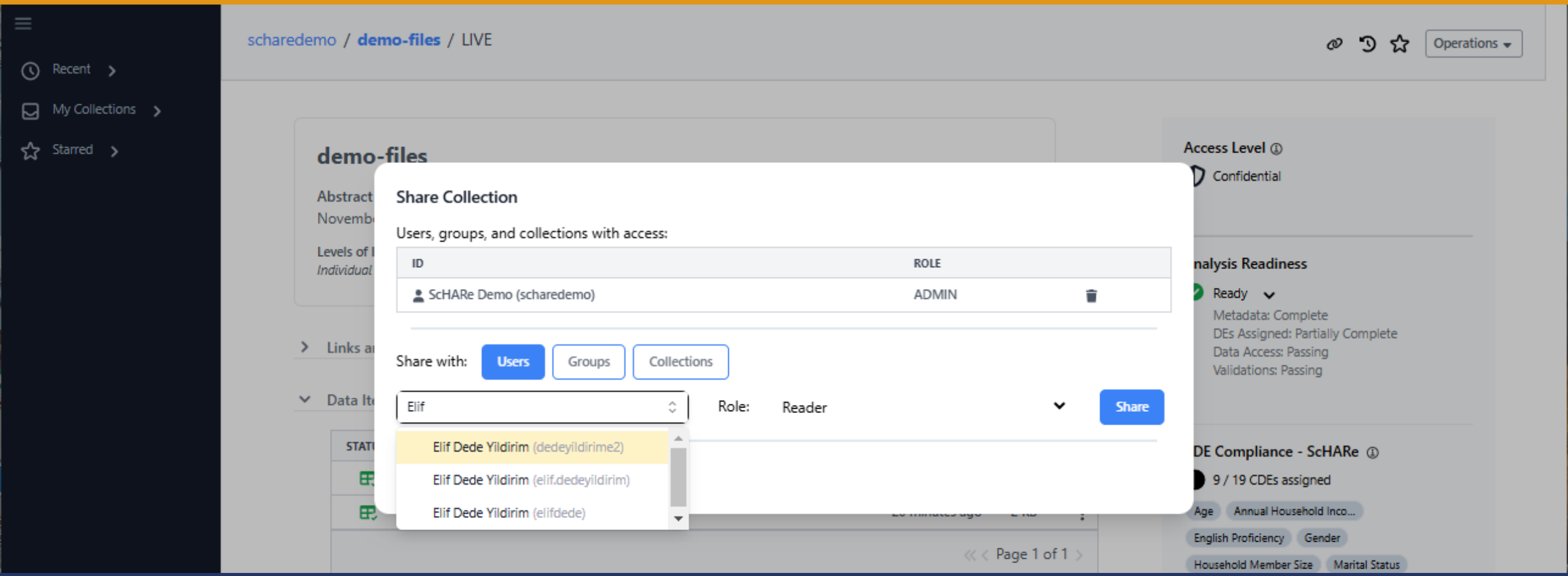
Search for a user...

Role: Reader

Share

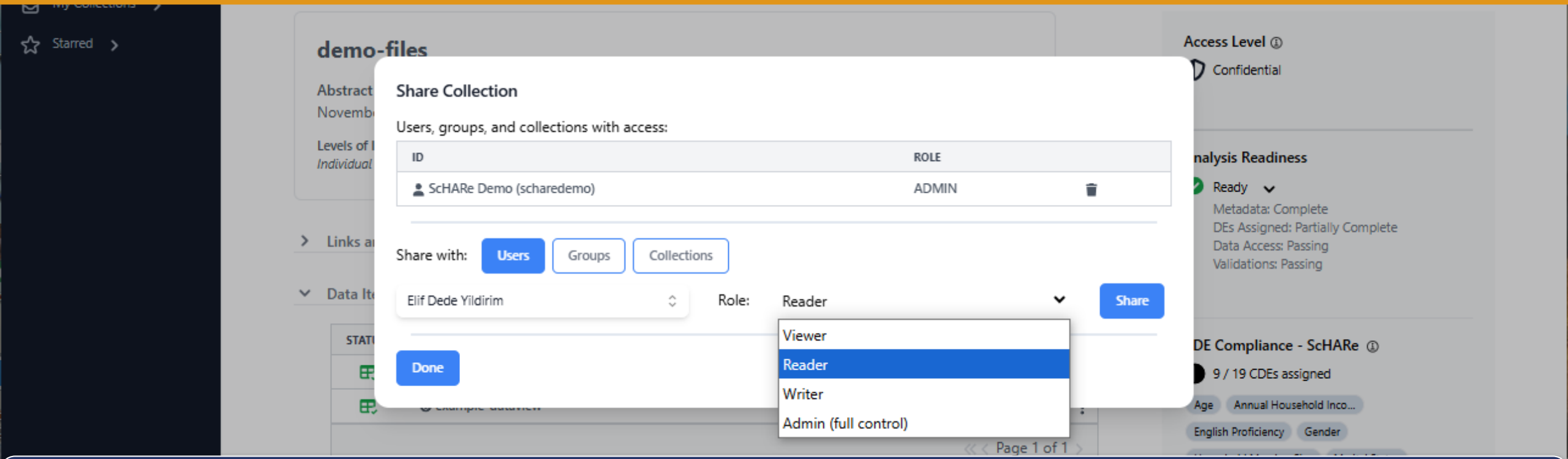
Done

Access Levels and Sharing Data



After changing your collection's access level to Confidential, you can share it with other users, groups, and collections.

Access Levels and Sharing Data



Access Levels

The access level of a collection defines the maximum permissions that can be used to share it with others. The following access levels are supported:

- **Private**: Only the collection's owner can access
- **Confidential**: The collection can be shared with named users
- **Controlled**: The collection can be shared with members of a controlled access group, as well as named users
- **Public**: The collection can be read by any user, including those not logged in; it can also be shared with named users

Access Levels and Sharing Data

ScHARe Repository

About Docs Collections CDEs

Search...

scharedemo

Collection authorization successfully updated.

Recent

My Collections

Starred

scharedemo / demo-files / LIVE

Operations

demo

Abstract

Novemb

Levels of

Individual

Links a

Data It

STAT

Page 1 of 1

Drag and Drop or Browse Files to Upload

Access Level

Confidential

nalysis Readiness

Ready

Metadata: Complete

DEs Assigned: Partially Complete

Data Access: Passing

Validations: Passing

DE Compliance - ScHARe

9 / 19 CDEs assigned

Age | Annual Household Inco... | English Proficiency | Gender | Household Member Size | Marital Status | Postal Zip Code | Race/Ethnicity Self-Ide... | Sex at Birth

Share Collection

Users, groups, and collections with access:

ID	ROLE
ScHARe Demo (scharedemo)	ADMIN
Elif Dede Yildirim (elifdede)	READER

Share with: Users | Groups | Collections

Search for a user...

Role: Reader

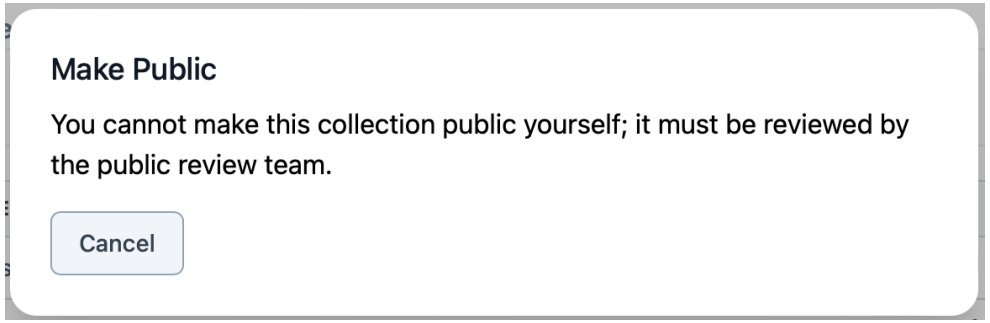
Share

Done

Publishing Data

We are still working on the final version of the process; however, it will essentially be:

1. Prepare your data according to the published guidelines
2. Add the Public Review group as Admin on your collection
   a. This is necessary for them to be able to alter your collection's Access Level on your behalf
3. Notify the Public Review group by email
   a. They will review your data for compliance with the data sharing guidelines
   b. If any changes are necessary, you can work with the reviewer
   c. Once complete, they will create a static version of your collection and set its Access Level to Public



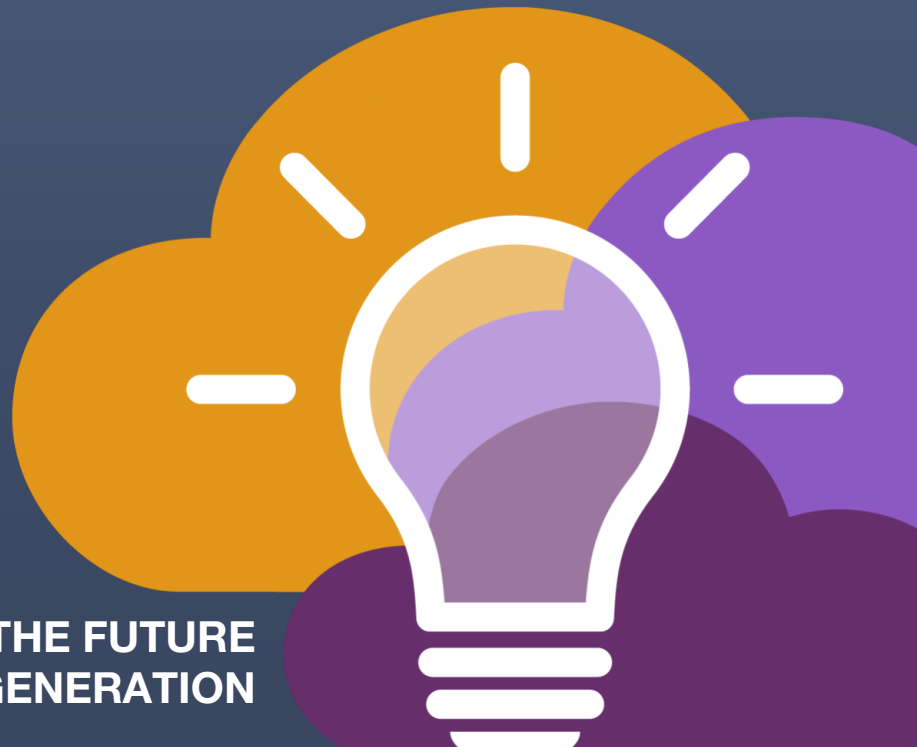
ScHARe Repository
Introduction

November 20, 2024

Deborah Duran, PhD · NIMHD
Elif Dede Yildirim, PhD · NIMHD
Mark Aronson, PhD · NIMHD

ScHARe

Data Aggregation



BE A PART OF THE FUTURE
OF KNOWLEDGE GENERATION

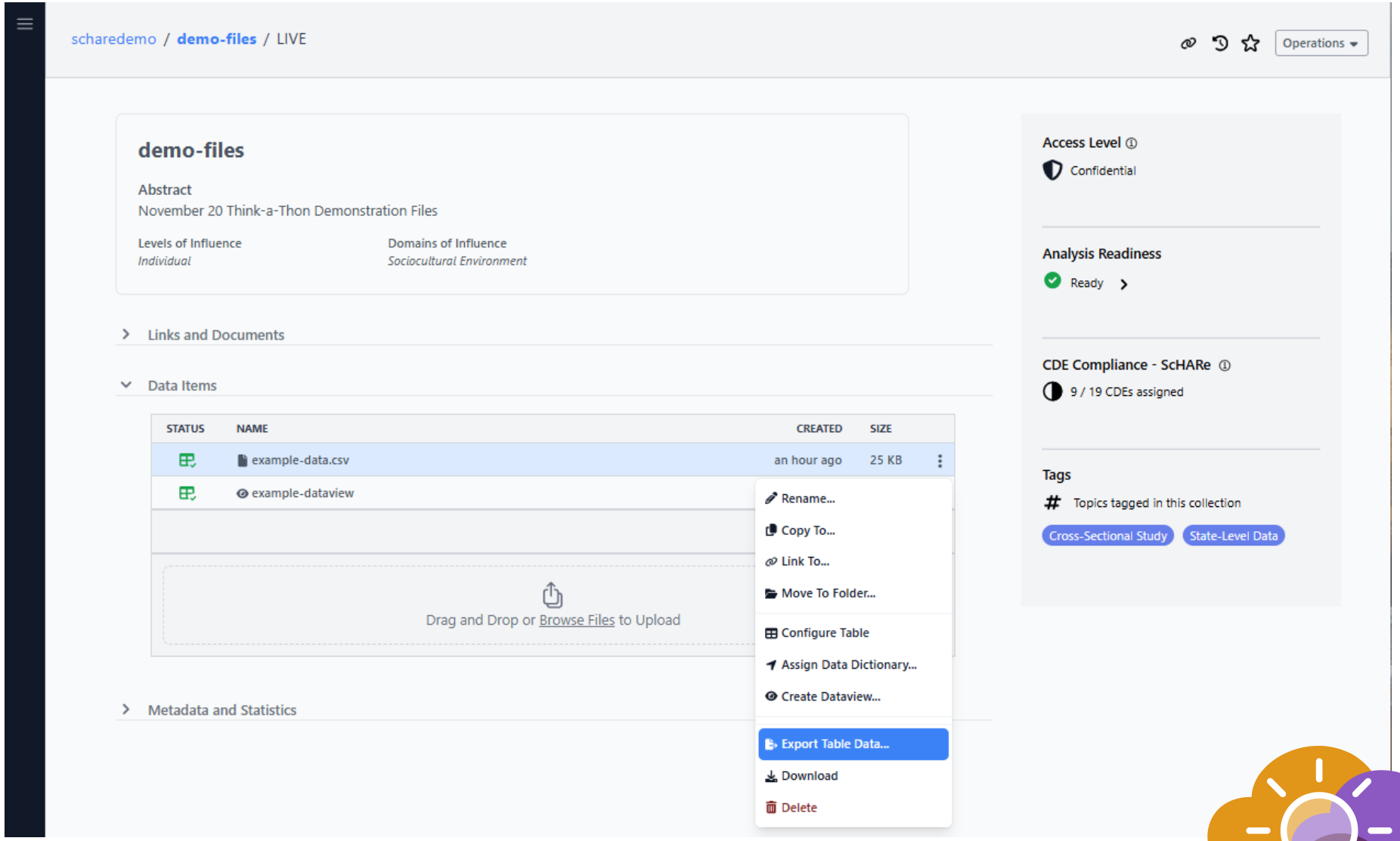
Downloading data to your own computer

Use the item's menu to download the original file

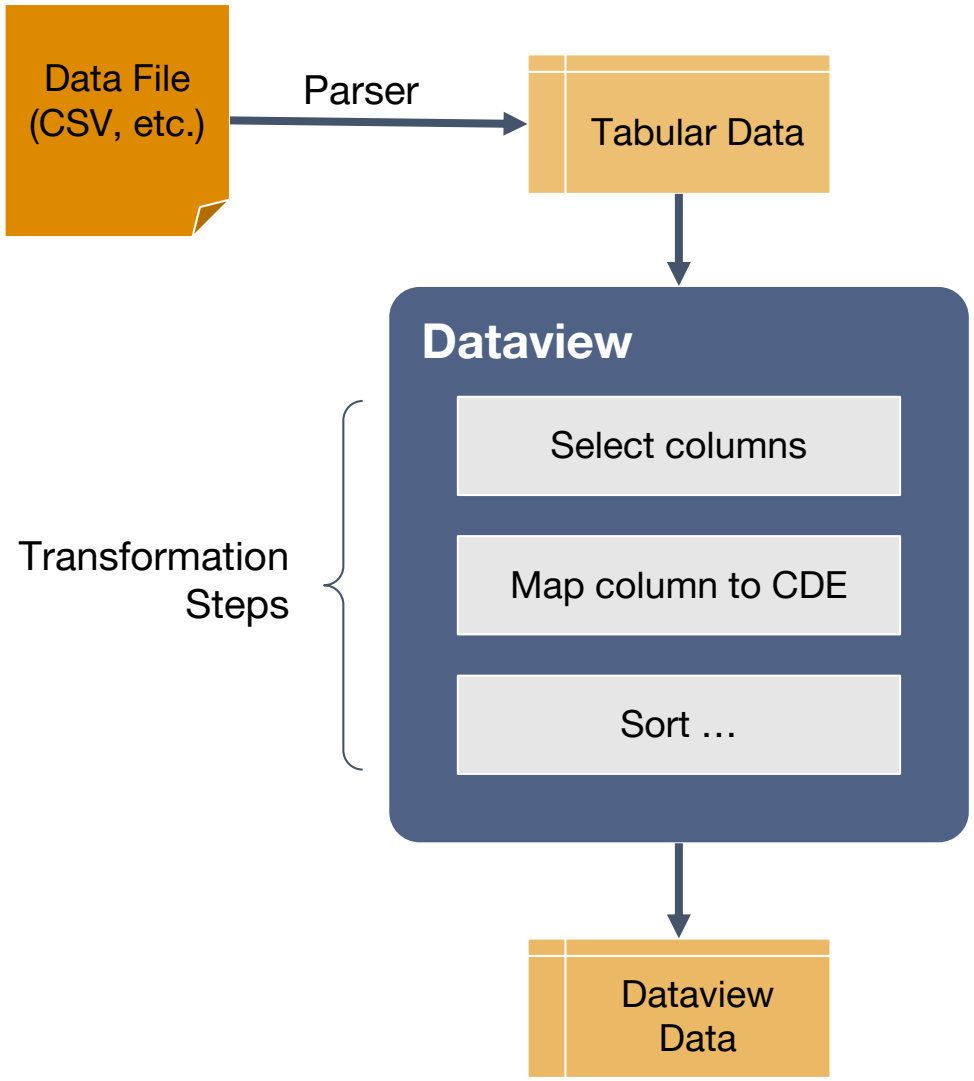
- Best for working directly with raw data

You can also export and download the tabular data in CSV, TSV, or Parquet format

- Best for working with mapped data, summary data, and other processed data



Using Dataviews to Aggregate Data

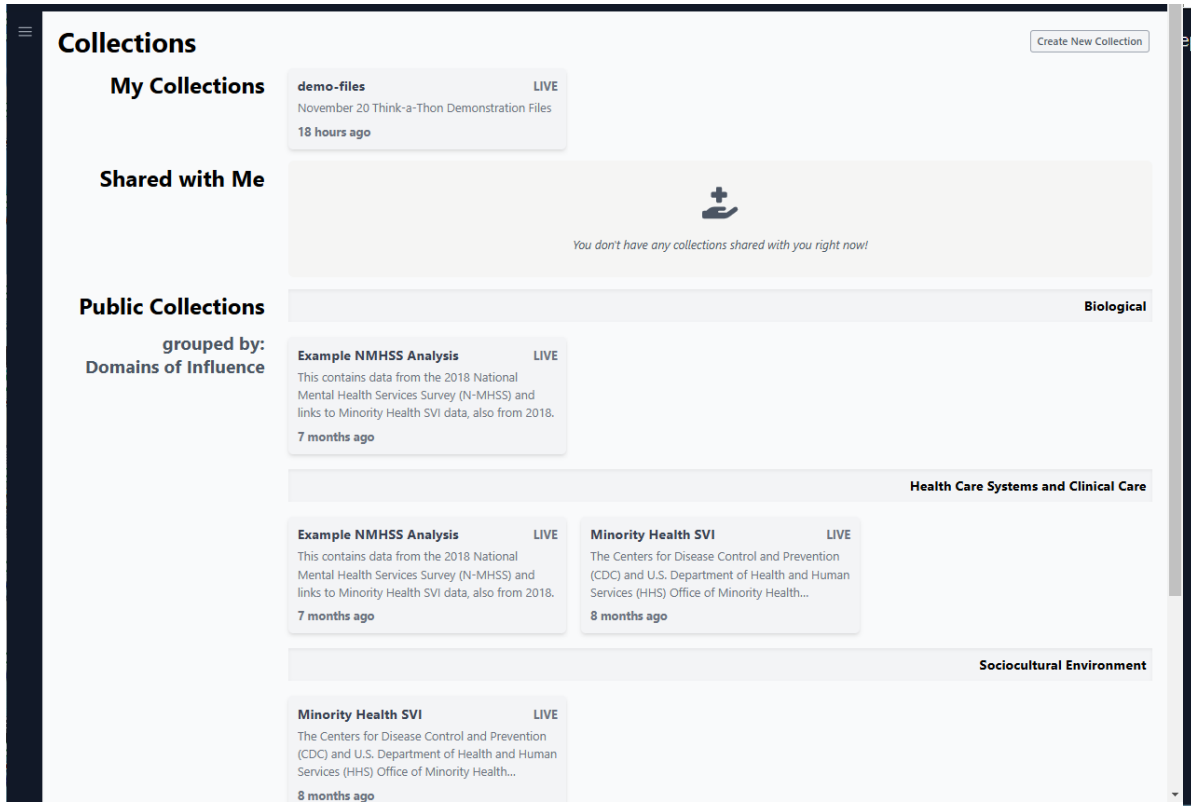


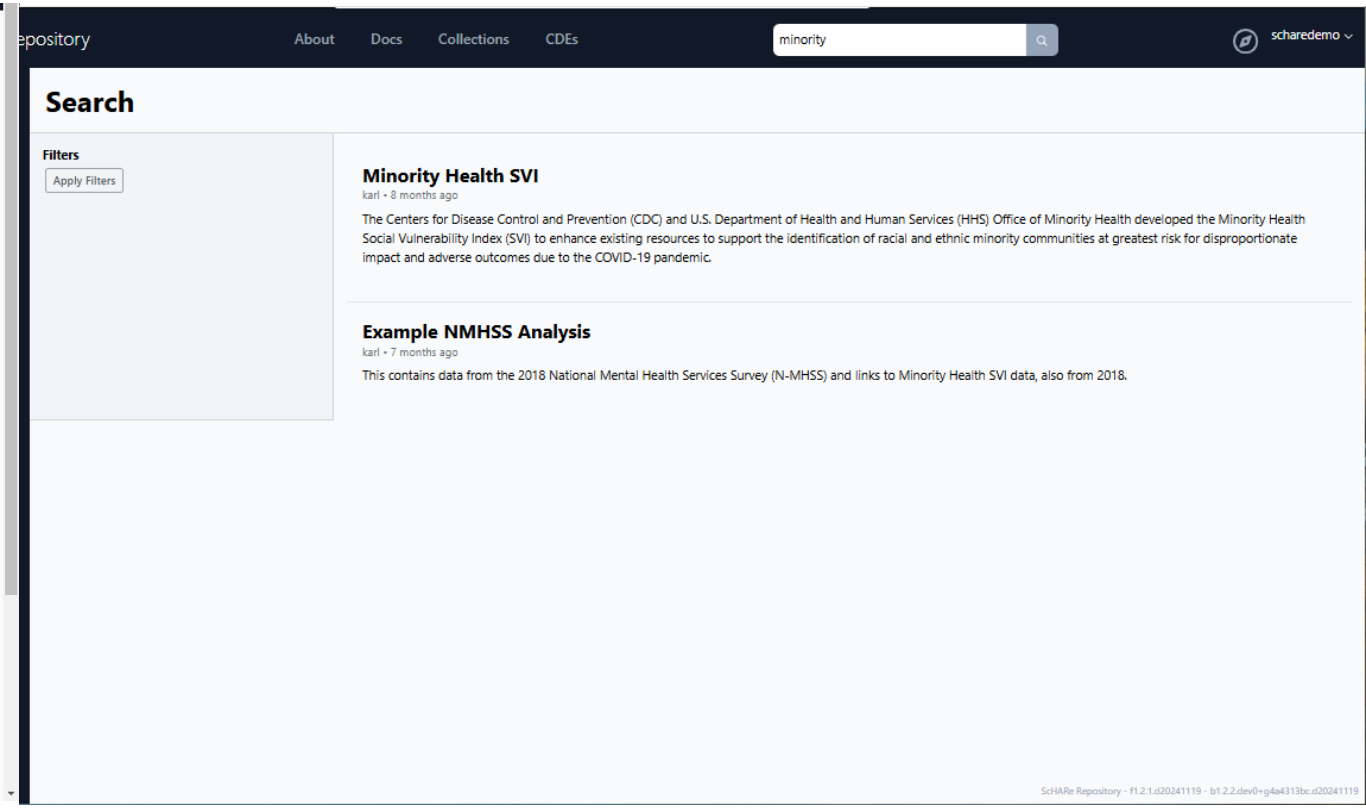
Dataviews take data from one or more sources, apply a series of transformation steps to that data *(filtering, sorting, mapping, etc.)* resulting in a new table of data as output.

Uses of Dataviews:

- Creating subsets of data
- Hiding PHI/PII for publishing
- Summarizing individual-level data into subsets and estimates
- **Joining multiple datasets together**
- Mapping to CDEs
- … many others!

Browsing and Searching for Data

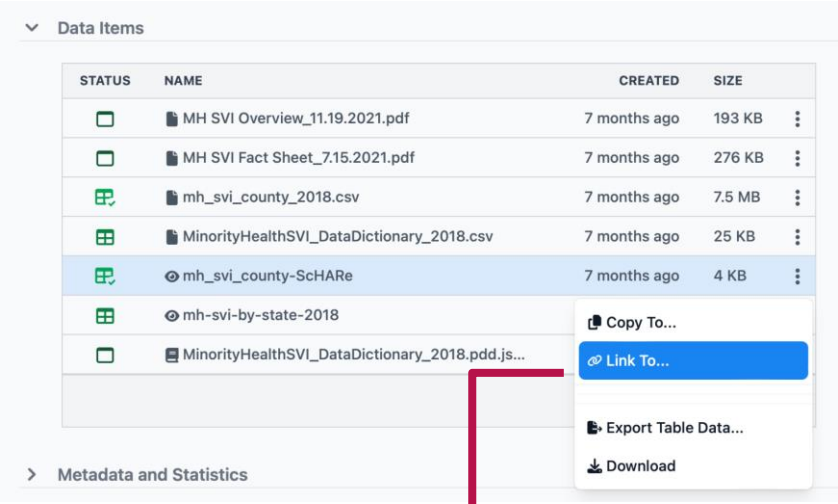


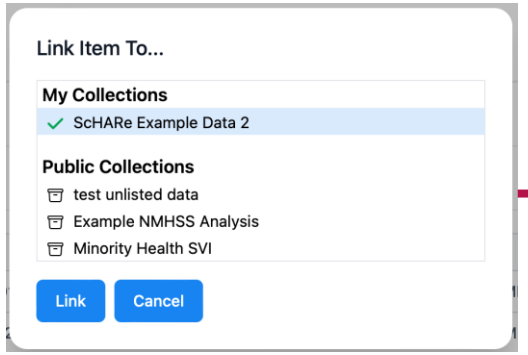


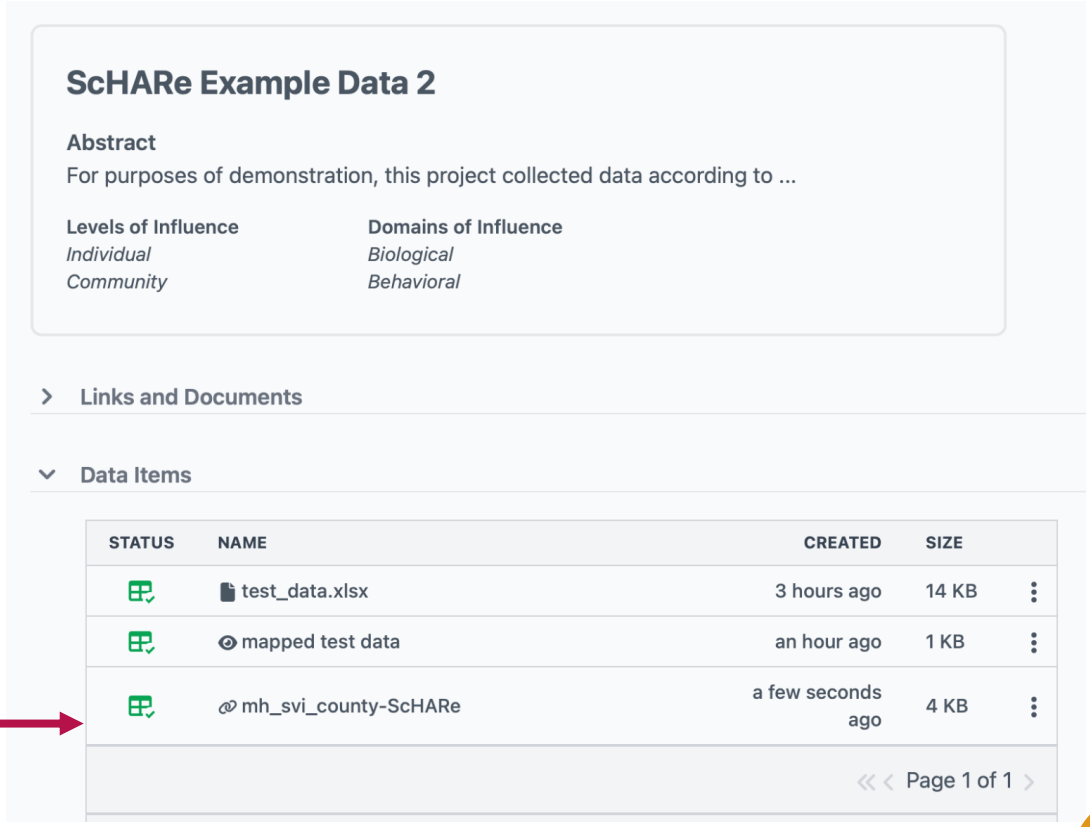
Look for improvements to the data organization and search experience in 2025!

Linking and Aggregating Data

If you find public data that you would like to combine with your project data, you can link it into your own collection and use it just like a file that you had uploaded yourself.







Linking and Aggregating Data

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Minority Health SVI

Abstract

The Centers for Disease Control and Prevention (CDC) and U.S. Department of Health and Human Services (HHS) Office of Minority Health developed the Minority Health Social Vulnerability Index (SVI) to enhance existing resources to support the identification of racial and ethnic minority communities at greatest risk for disproportionate impact and adverse outcomes due to the COVID-19 pandemic.

Levels of Influence
Community
Societal

Domains of Influence
Health Care Systems and Clinical Care
Sociocultural Environment

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	MH SVI Overview_11.19.2021.pdf	8 months ago	193 KB
	MH SVI Fact Sheet_7.15.2021.pdf	8 months ago	276 KB
	mh_svi_county_2018.csv	8 months ago	7.5 MB
	MinorityHealthSVI_DataDictionary_2018.csv	8 months ago	25 KB
	mh_svi_county-ScHARe	8 months ago	4 KB
	mh-svi-by-state-2018	7 months ago	2 KB
	MinorityHealthSVI_DataDictionary_2018.pdd.json	5 months ago	87 KB

Page 1 of 1

Metadata and Statistics

Access Level
Public

Analysis Readiness
Ready

CDE Compliance - ScHARe
1 / 19 CDEs assigned

Tags
Topics tagged in this collection

Minority Health | Household Income | Household size | Race | Health Care Delivery

Linking Data

My Collections

Starred

Minority Health SVI

Abstract

The Centers for Disease Control and Prevention (CDC) and U.S. Department of Health and Human Services (HHS) Office of Minority Health developed the Minority Health Social Vulnerability Index (SVI) to enhance existing resources to support the identification of racial and ethnic minority communities at greatest risk for disproportionate impact and adverse outcomes due to the COVID-19 pandemic.

Levels of Influence	Domains of Influence
Community	*Health Care Systems and Clinical Care*
Societal	*Sociocultural Environment*

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	MH SVI Overview_11.19.2021.pdf	8 months ago	193 KB
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	mh_svi_county_2018.csv	8 months ago	7.5 MB
	MinorityHealthSVI_DataDictionary_2018.csv	8 months ago	25 KB
	mh_svi_county-ScHARe	8 months ago	4 KB
	mh-svi-by-state-2018		
	MinorityHealthSVI_DataDictionary_2018.pdd.json		

Copy To...

Link To...

Export Table Data...

Download

Metadata and Statistics

Access Level

Public

Analysis Readiness

Ready

CDE Compliance - ScHARe

1 / 19 CDEs assigned

Tags

Topics tagged in this collection

Minority Health | Household Income | Household size | Race | Health Care Delivery

Linking Data

Recent
My Collections
Starred

Minority Health SVI

Abstract

The Centers for Disease Control and Prevention (CDC) and U.S. Department of Health and Human Services (HHS) Office of Minority Health developed the Minority Health Social Vulnerability Index (SVI) to enhance existing resources to support the identification of racial and ethnic minority communities at greatest risk for disproportionate impact and adverse outcomes due to the COVID-19 pandemic.

Levels of Influence
Community
Societal

Domains of Influence
Health Care
Sociocultura

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	MH SVI Overview_11.19.2021.pdf	months ago	193 KB
	MH SVI Fact Sheet_7.15.2021.pdf	months ago	276 KB
	mh_svi_county_2018.csv	8 months ago	7.5 MB
	MinorityHealthSVI_DataDictionary_2018.csv	8 months ago	25 KB
	mh_svi_county-ScHARe	8 months ago	4 KB
	mh-svi-by-state-2018	7 months ago	2 KB
	MinorityHealthSVI_DataDictionary_2018.pdd.json	5 months ago	87 KB

Page 1 of 1

Metadata and Statistics

Link Item To...

My Collections
demo-files

Public Collections
ScHARe Think-a-Thon - Example Data
test unlisted data
Example NMHSS Analysis
Minority Health SVI

Link Cancel

Access Level
Public

Analysis Readiness
Ready

CDE Compliance - ScHARe
1 / 19 CDEs assigned

Tags
Topics tagged in this collection
Minority Health
Household Income
Household size
Race
Health Care Delivery

Linking Data

Recent
My Collections
Starred

scharedemo / demo-files / LIVE

Operations

demo-files

Abstract
November 20 Think-a-Thon Demonstration Files

Levels of Influence
Individual

Domains of Influence
Sociocultural Environment

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	example-data.csv	8 hours ago	25 KB
	example-dataview	7 hours ago	2 KB
	mh_svi_county-ScHARe	a few seconds ago	4 KB

Page 1 of 1

Drag and Drop or Browse Files to Upload

Metadata and Statistics

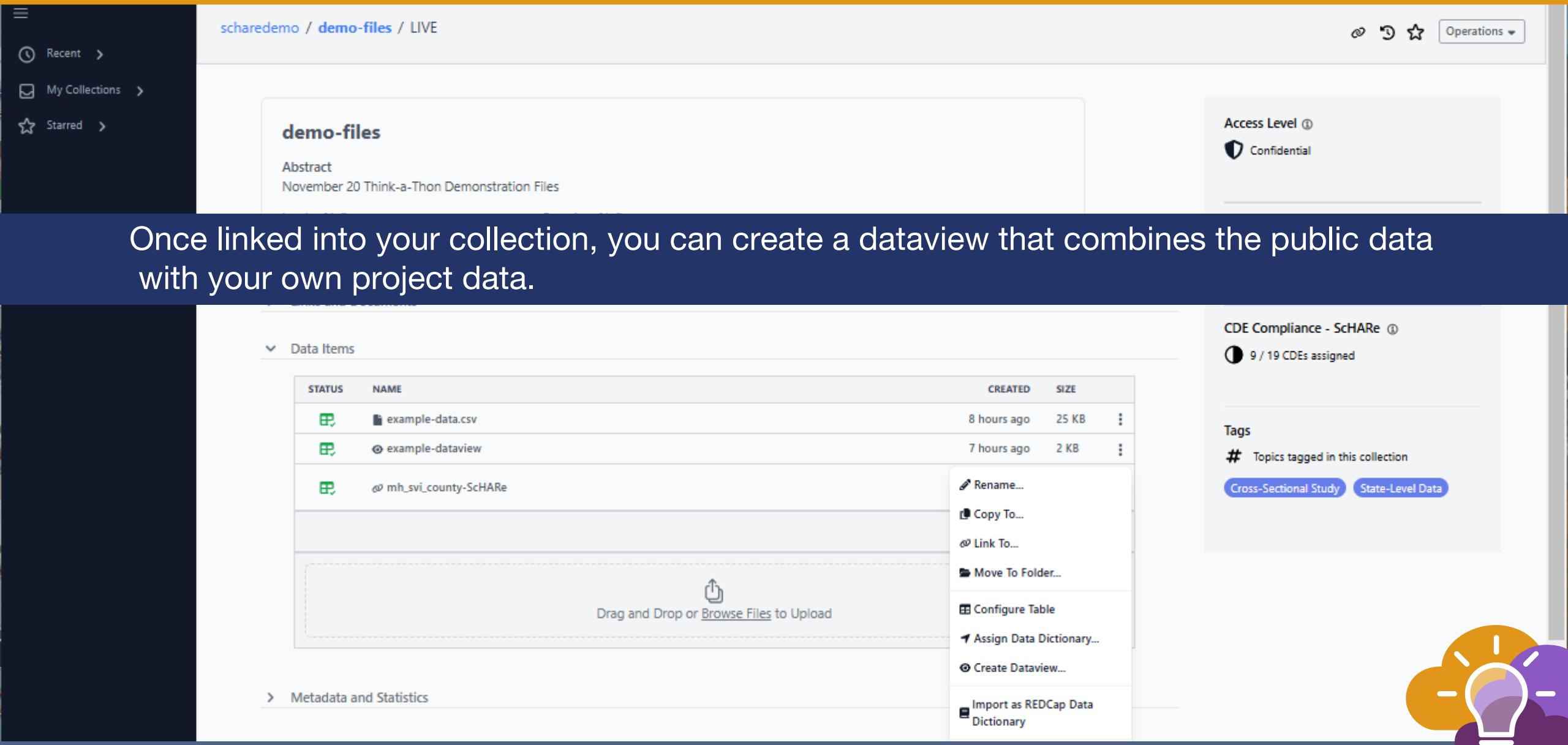
Access Level
Confidential

Analysis Readiness
Ready

CDE Compliance - ScHARe
9 / 19 CDEs assigned

Tags
Topics tagged in this collection
Cross-Sectional Study
State-Level Data

Aggregating Data



Once linked into your collection, you can create a dataview that combines the public data with your own project data.

Aggregating Data

My Collections
Starred

demo-files

Abstract
November 20 Think-a-Thon Demonstration Files

Levels of Influence
Individual

Domains of Influence
Sociocultural Environment

Links and Documents

Data Items

STATUS	NAME	CREATED	SIZE
	example-data.csv	8 hours ago	25 KB
	example-dataview	7 hours ago	2 KB
	mh_svi_county-ScHARe	minutes ago	4 KB

Page 1 of 1

Drag and Drop or Browse Files to Upload

Create Dataview

aggregated_data

Create Dataview | Cancel

Metadata and Statistics

Access Level
Confidential

Analysis Readiness
Ready

CDE Compliance - ScHARe
9 / 19 CDEs assigned

Tags
Topics tagged in this collection
Cross-Sectional Study | State-Level Data

Aggregating Data

Recent
My Collections
Starred

scharedemo / **demo-files** / LIVE / aggregated_data

Advanced Explorer Table Dictionary Meta 575 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example-dataview

Take

Number of rows Range of rows Limit output to Number of Rows

10

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

- Select Columns
- Filter Rows
- Sort
- Shuffle
- Join
- Take Rows
- Rename Column
- Map Column
- Aggregate Rows

Data available 0 parsing errors 0 validation errors

on Preview

		age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender	gender_select
		Years	no	no	no	yes	no	no	no	28752	Male	None of these describe me	Trans man / Tr Man/ FTM
		Years	yes	no	no	no	no	no	no	10032	Male	None of these describe me	Trans man / Tr
9784	18	Years	no	no	yes	no	no	yes	no	07501	Male	Trans	
5193	91	Years	no	no	no	no	yes	no	no	26726	None of these describe me	T	
8502	86	Years	yes	no	no	no	no	no	no	99737	Prefer not to answer	Pre to answer	

Aggregating Data

Starred

Advanced Explorer Table Dictionary Meta 575 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example-dataview

Take

Number of rows Range of rows Limit output to Number of Rows

10

Join Select

Join Table

Select table...

* Join table selection is required

Dataview Column

Select column...

* Column selection is required

Matching Column from Join Table

Select column...

* Column selection is required

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Transformation Incomplete

There are one or more errors in the transformation above. Please correct the errors to preview the transformation result.

Developer Data ›

Aggregating Data

Recent
My Collections
Starred

scharedemo / **demo-files** / LIVE / aggregated_data

Advanced Explorer Table Dictionary Meta 575 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example-dataview

Take

Number of rows Range of rows Limit output to Number of Rows

10

Join Select

Join Table	Dataview Column	Matching Column from Join Table
mh_svi_county-ScHARe	zip_code	zip_code

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Results › Data available 0 parsing errors 0 validation errors

Transformation Preview

record_id	age	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
1943	92	Years	no	no	no	yes	no	no	no	28752	Male	N th de me

Aggregating Data

Recent
My Collections
Starred

scharedemo / **demo-files** / LIVE / aggregated_data

Advanced Explorer Table Dictionary Meta 575 bytes | a few seconds ago | text/prql | status:

Item Operations

Source data from: example-dataview

Take

Number of rows Range of rows Limit output to Number of Rows

10

Join Select

Join Table	Dataview Column	Matching Column from Join Table
mh_svi_county-ScHARe	zip_code	zip_code

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

- Select Columns
- Filter Rows
- Sort
- Shuffle
- Join
- Take Rows
- Rename Column

Data available 0 parsing errors 0 validation errors

on Preview

	age_units	race_ethnicity_1	race_ethnicity_2	race_ethnicity_3	race_ethnicity_4	race_ethnicity_5	race_ethnicity_6	race_ethnicity_7	zip_code	sex_at_birth	gender
	Years	no	no	no	yes	no	no	no	28752	Male	N th de me

Selecting Variables

mh_svi_county-ScHARe | zip_code | zip_code

Select

Available Columns

- ST_ABBR
- FIPS
- M_TOTPOP
- E_HU
- M_HU
- E_HH

Add All »

Selected Columns

- zip_code
- gender_mapped
- sex_at_birth
- STATE
- COUNTY
- LOCATION
- E_TOTPOP

« Remove All

+ Add Step | Libraries: | Add Library | Add Data Elements | Clear Dataview | Save Dataview

Results › ✓ Data available ✓ 0 parsing errors ✓ 0 validation errors

Transformation Preview

record_id	age	zip_code	gender_mapped	sex_at_birth	STATE	COUNTY	LOCATION	E_TOTP
1943	92	28752	None of these describe me. I would like to consider additional options	Male	NORTH CAROLINA	Avery	Avery County, North Carolina	
1943	92	28752	None of these describe me. I would like to consider additional options	Male	NORTH CAROLINA	Rutherford	Rutherford County, North Carolina	
1210	72	52223	Man	Female	IOWA	Delaware	Delaware County, Iowa	

Selecting Variables

Add All » « Remove All

+ Add Step Libraries: Add Library Add Data Elements Clear Dataview Save Dataview

Results › ✓ Data available ✓ 0 parsing errors ✓ 0 validation errors

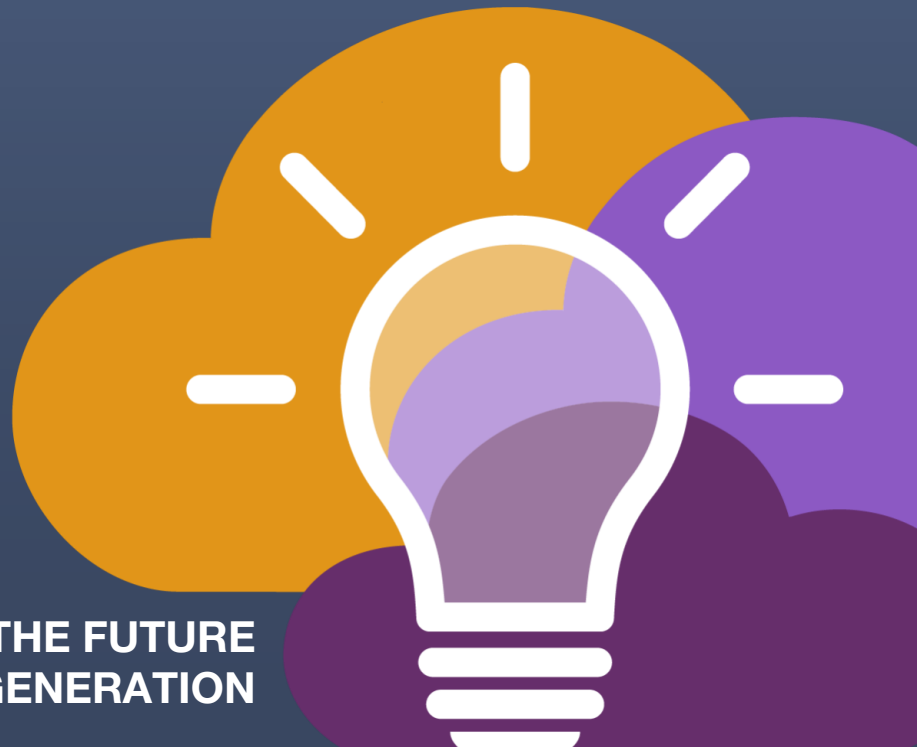
Transformation Preview

record_id	age	zip_code	gender_mapped	sex_at_birth	STATE	COUNTY	LOCATION	E_TOTPOP
1943	92	28752	None of these describe me. I would like to consider additional options	Male	NORTH CAROLINA	Avery	Avery County, North Carolina	17501
1943	92	28752	None of these describe me. I would like to consider additional options	Male	NORTH CAROLINA	Rutherford	Rutherford County, North Carolina	66532
1210	72	52223	Man	Female	IOWA	Delaware	Delaware County, Iowa	17258
1943	92	28752	None of these describe me. I would like to consider additional options	Male	NORTH CAROLINA	McDowell	McDowell County, North Carolina	45109
8502	86	99737	Prefer not to answer	Prefer not to answer	ALASKA	Southeast Fairbanks	Southeast Fairbanks Census Area, Alaska	6876
9784	18	07501	Transgender	Male	NEW JERSEY	Passaic	Passaic County, New Jersey	504041
2618	80	35405	Prefer not to answer	Male	ALABAMA	Tuscaloosa	Tuscaloosa County, Alabama	206213
6809	58	11769	Transgender	None of these describe me	NEW YORK	Suffolk	Suffolk County, New York	1487901
6688	76	10032	None of these describe me. I would like to consider additional options	Male	NEW YORK	New York	New York County, New York	1632480
5193	91	26726	Transgender	None of these describe me	WEST VIRGINIA	Grant	Grant County, West Virginia	11641
3563	79	53186	Transgender	None of these describe me	WISCONSIN	Waukesha	Waukesha County, Wisconsin	398879
5193	91	26726	Transgender	None of these describe me	WEST VIRGINIA	Mineral	Mineral County, West Virginia	27278
1172	46	37208	Woman	Prefer not to answer	TENNESSEE	Davidson	Davidson County, Tennessee	6[illegible]

rows per page: 25

ScHARe

Data Analysis

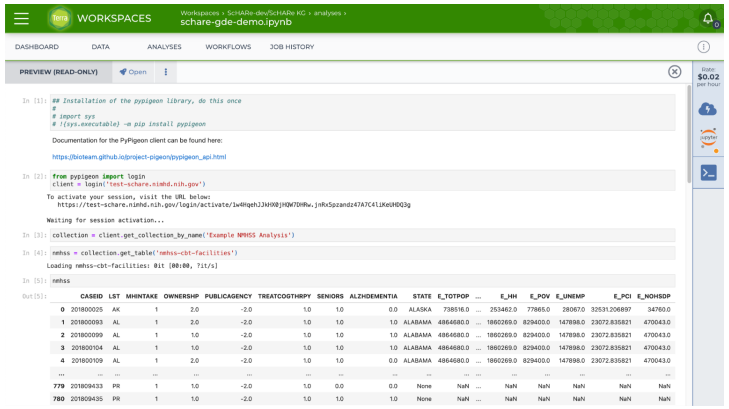


BE A PART OF THE FUTURE
OF KNOWLEDGE GENERATION

How do I analyze or aggregate data from the ScHARe Repository?

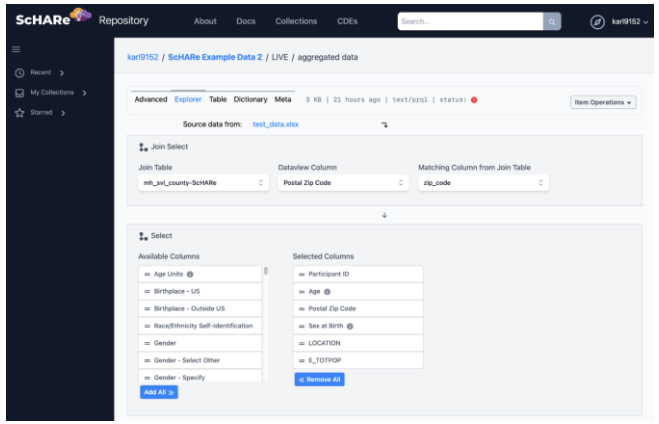
Three quick options:

Connect to a Terra Jupyter notebook



Download to your own computer

Use Dataviews on the Repository



Look for a future Think-a-Thon where we will share more about how to link your data to Terra and how to use the ScHARe Repository to create aggregated data sets!

Analyzing Data on Terra (Jupyter Notebooks)

Terra WORKSPACES

Workspaces › ScHARe-dev/ScHARe KG › analyses ›
schare-gde-demo.ipynb

DASHBOARD DATA ANALYSES WORKFLOWS JOB HISTORY

PREVIEW (READ-ONLY) Open

Rate: $0.02 per hour

In [1]:
```
## Installation of the pypigeon library, do this once
#
# import sys
# !{sys.executable} -m pip install pypigeon
```

Documentation for the PyPigeon client can be found here:

https://bioteam.github.io/project-pigeon/pypigeon_api.html

In [2]:
```
from pypigeon import login
client = login('test-schare.nimhd.nih.gov')
```

```
To activate your session, visit the URL below:
  https://test-schare.nimhd.nih.gov/login/activate/1w4HqehJJkHX0jHQW7DHRw.jnRx5pzandz47A7C4liKeUHDQ3g

Waiting for session activation...
```

In [3]:
```
collection = client.get_collection_by_name('Example NMHSS Analysis')
```

In [4]:
```
nmhss = collection.get_table('nmhss-cbt-facilities')
```

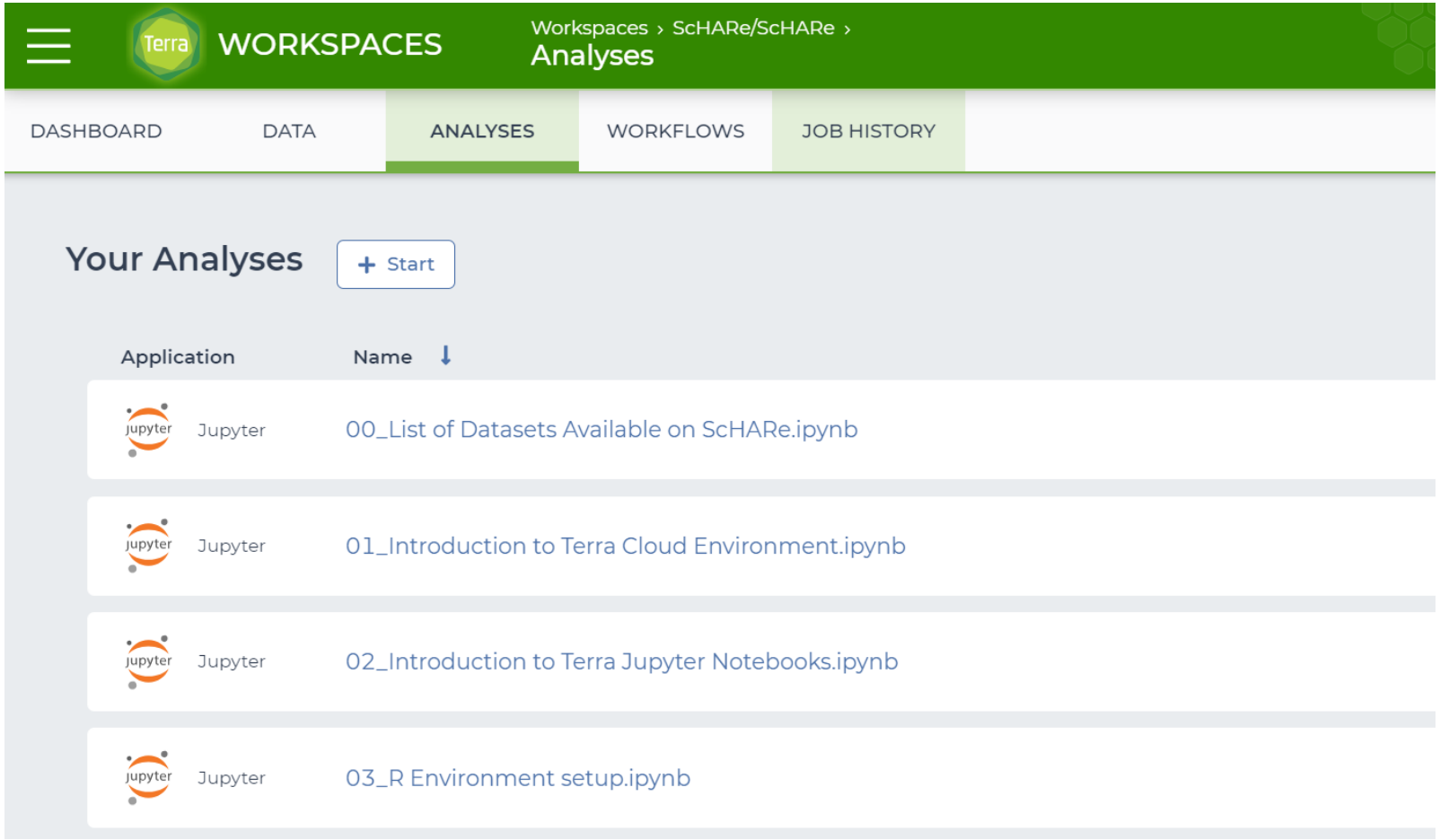
```
Loading nmhss-cbt-facilities: 0it [00:00, ?it/s]
```

In [5]:
```
nmhss
```

Out[5]:

	CASEID	LST	MHINTAKE	OWNERSHP	PUBLICAGENCY	TREATCOGTHRPY	SENIORS	ALZHDEMENTIA	STATE	E_TOTPOP	...	E_HH	E_POV	E_UNEMP	E_PCI	E_NOHSDP
0	201800025	AK	1	2.0	-2.0	1.0	1.0	0.0	ALASKA	738516.0	...	253462.0	77865.0	28067.0	32531.206897	34760.0
1	201800093	AL	1	2.0	-2.0	1.0	1.0	1.0	ALABAMA	4864680.0	...	1860269.0	829400.0	147898.0	23072.835821	470043.0
2	201800099	AL	1	1.0	-2.0	1.0	1.0	1.0	ALABAMA	4864680.0	...	1860269.0	829400.0	147898.0	23072.835821	470043.0
3	201800104	AL	1	1.0	-2.0	1.0	1.0	1.0	ALABAMA	4864680.0	...	1860269.0	829400.0	147898.0	23072.835821	470043.0
4	201800109	AL	1	2.0	-2.0	1.0	1.0	0.0	ALABAMA	4864680.0	...	1860269.0	829400.0	147898.0	23072.835821	470043.0
...	...	...	...	...	...	...	...	...	...	...	...	...	...	...	...	...
779	201809433	PR	1	1.0	-2.0	1.0	0.0	0.0	None	NaN	...	NaN	NaN	NaN	NaN	NaN
780	201809435	PR	1	1.0	-2.0	1.0	1.0	1.0	None	NaN	...	NaN	NaN	NaN	NaN	NaN

Analyzing Data on Terra (Jupyter Notebooks)



Analyzing Data on Terra (Jupyter Notebooks)

Terra WORKSPACES

Workspaces › ScHARe/ScHARe › analyses ›
07_How to access plot and save data from ScHARe hosted datasets using Python 3.ipynb

DASHBOARD DATA ANALYSES WORKFLOWS JOB HISTORY

PREVIEW (READ-ONLY) Open

Load dataset into a dataframe in our notebook Virtual Machine

Let's now get all of the data and load it into a pandas dataframe in our notebook Virtual Machine.

Pandas (http://pandas.pydata.org/pandas-docs/stable/) is a popular Python package for data manipulation to the Cloud Environment Virtual Machine running this notebook.

A dataframe is a 2-dimensional labeled data structure with columns of potentially different types. You can think of it like a spreadsheet or table. It is generally the most commonly used pandas object.

In [5]:
```
# Let's create a dataframe. We will use the file location path copied earlier.
# Filepath = 'gs://fc-secure-d6e25d73-4b50-4dbc-ac10-ec689987eaa9/uploads/HealthBehaviors/BRFSS2021.csv'

BRFSS_table = pandas.read_csv("gs://fc-secure-d6e25d73-4b50-4dbc-ac10-ec689987eaa9/uploads/HealthBehaviors/BRFSS2021.csv", sep=',')
```

We have created our dataframe. Let's now take a look at the top of our table:

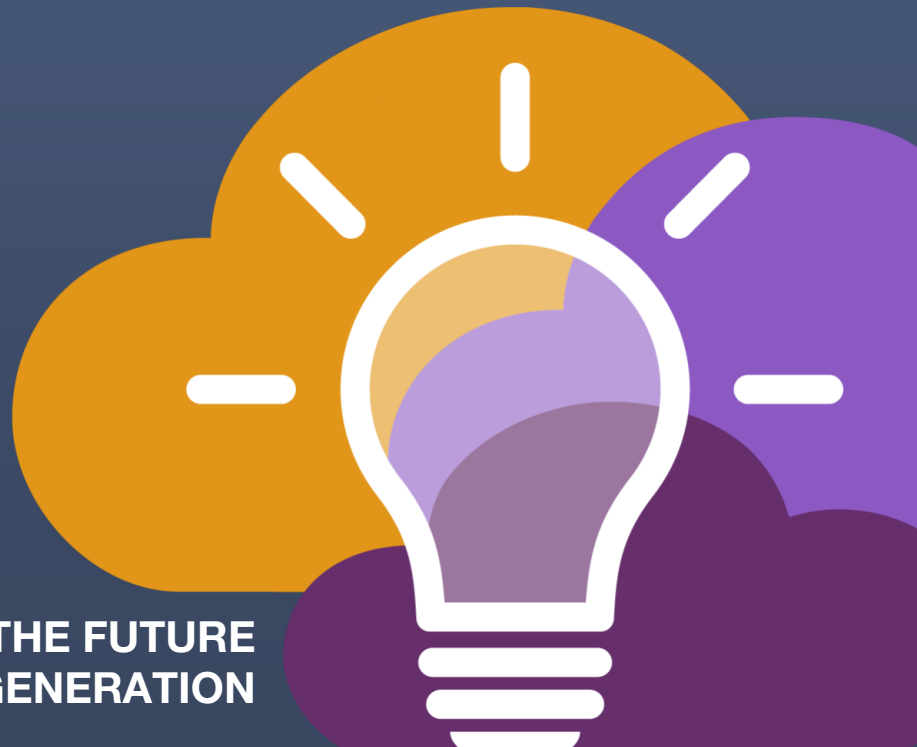
In [6]:
```
BRFSS_table.head()
```

Out[6]:

	_state	fmonth	idate	imonth	iday	iyear	dispcode	seqno	_psu	ctelenm1	...	_frtres1	_vegres1	_frutsu1	_vegesu1	_frtlt1a	_veglt1a	_frt16a	_veg23a	_fruit
0	1	1	1192021	1	19	2021	1100	2021000001	2021000001	1.0	...	1	1	100.0	214.0	1	1	1	1	
1	1	1	1212021	1	21	2021	1100	2021000002	2021000002	1.0	...	1	1	100.0	128.0	1	1	1	1	
2	1	1	1212021	1	21	2021	1100	2021000003	2021000003	1.0	...	1	1	100.0	71.0	1	2	1	1	

ScHARe

Conclusion



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OF KNOWLEDGE GENERATION

ScHARe Terra

In Summary:

- Register for the ScHARe/Terra Platform
- Access federated data – especially SDoH and population science
- Create your own workspace – can share with others
- Assess computational tools, such as python and R coding

ScHARe Repository

In Summary: (Comply with the NIH Data Management and Sharing Policy Requirement)

- When getting started, first create a collection, provide metadata, and upload documents.
- Upload your data and use the system to help you map to the ScHARe CDEs.
- View your data, see CDE compliance and analysis readiness.
- Data can be shared with your colleagues, and can be made publicly available after review.
- You can use dataviews to create subsets of your data, join datasets together and more.
- Data can also be analyzed on the ScHARe Terra workspace.

We are here to support you!

We want to hear your questions, issues and comments about the ScHARe Repository!

For any questions regarding how to use the Repository, please reach out to:

✉ schare@mail.nih.gov

Response time: within 24 hours

For Technical Support inquiries, contact:

✉ schare-repository-support@bioteam.net

🕓 Office Hours: Wednesdays, 4-5 PM US Eastern

Questions?

Slido Poll

What concerns or barriers do you have regarding sharing your data publicly?

Think-a-Thon poll

1. Rate how useful this session was:

- ☐ Very useful
- ☐ Useful
- ☐ Somewhat useful
- ☐ Not at all useful

Think-a-Thon poll

2. Rate the pace of the instruction for yourself:

- ☐ Too fast
- ☐ Adequate for me
- ☐ Too slow

Think-a-Thon poll

3. How likely will you participate in the next Think-a-Thon?

- ☐ Very interested, will definitely attend
- ☐ Interested, likely will attend
- ☐ Interested, but not available
- ☐ Not interested in attending any others

ScHARe

Thank you

ScHARe

Next Think-a-Thons:

bit.ly/think-a-thons

Register for ScHARe:

bit.ly/join-schare

schare@mail.nih.gov