ScHARe

Think-a-Thons

National Institutes of Health

Computational Data Science Strategies

Getting Ready for a Data Science 101 Course

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January 17, 2024

ScHARe

Science
collaborative for
Health disparities and
Artificial intelligence bias
Reduction

Thank you

NIMHD

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ODSS

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NIH/OD

Dr. Larry Tabak

NINR

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STRIDES

Terra

SIDEM

RLA

Broad Institute

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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	☐	☐	☐	☐

ScHARe

Overview

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 three 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 healthy disparity, and health and healthcare delivery outcomes research
- **Advance AI bias mitigation and ethical inquiry** by developing innovative strategies and securing diverse perspectives

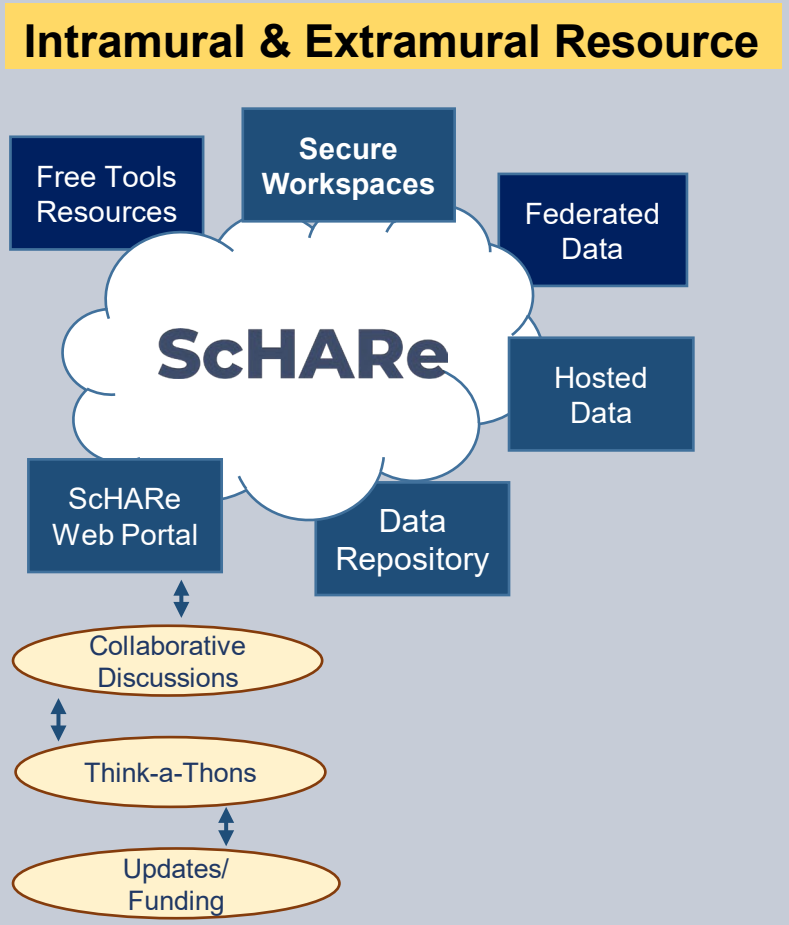
nimhd.nih.gov/schare

ScHARe Components

ScHARe co-localizes within the cloud:

- **Datasets** (including social determinants of health and social science data) relevant to minority health, health disparities, and health care outcomes research
- **Data repository** to comply with the required hosting, managing, and sharing of data from NIMHD- and NINR-funded research programs
- **Computational capabilities and secure, collaborative workspaces** for students and all career level researchers
- **Tools for collaboratively evaluating and mitigating biases** associated with datasets and algorithms utilized to inform healthcare and policy decisions

Frameworks: Google Platform, Terra, GitHub, NIMHD Web ScHARe Portal



nimhd.nih.gov/schare

ScHARe Data Ecosystem

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

- **Google Cloud Public Datasets:** publicly accessible, federated, de-identified datasets hosted by Google through the Google Cloud Public Dataset Program

  Example: *American Community Survey (ACS)*

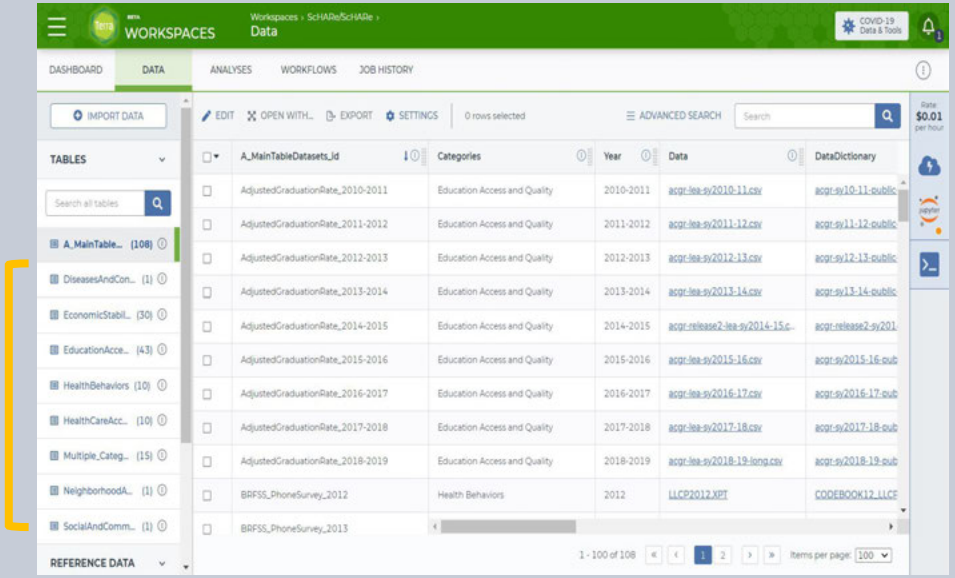
- **ScHARe Hosted Public Datasets:** publicly accessible, de-identified datasets hosted by ScHARe

  Example: *Behavioral Risk Factor Surveillance System (BRFSS)*

- **Funded Datasets on ScHARe:** publicly accessible and controlled-access, funded program/project datasets using Core Common Data Elements shared by NIH grantees and intramural investigators to comply with the NIH Data Sharing Policy

  Examples: *Jackson Heart Study (JHS); Extramural Grant Data; Intramural Project Data*

OVER 240 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**

Users will be able to **map and link** across datasets

ScHARe Data Ecosystem Structure

FEDERATED PUBLIC DATA 240+

Hosted by Google & ScHARe

REPOSITORY

CDE FOCUSED

CDEs enhances Data Interoperability (Aggregation) by using semantic standards and concept codes

Innovative Approach:

CDE Concept Codes Uniform Resource Identifier (URI)

What is a CDE?

A common data element (CDE) is a standardized, precisely defined question that is paired with a set of specific allowable responses, that is then used systematically across different sites, studies, or clinical trials to ensure consistent data collection

ScHARe CDEs Labels

For FUNDED PROJECT DATA – Common Data Elements Centralized for Interoperability and Data Sharing

- 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 (Associated Medications/Treatments)

NIH Endorsed

**NIMHD Framework
**Health Disparity Outcomes

(** project level CDE)

NIH CDE Repository: https://cde.nlm.nih.gov/home

Cross-walked with PhenX SDoH

NIH-endorsed CDEs have been reviewed and approved by an expert panel, and meet established criteria. They are designated with a gold ribbon.

COMMON DATA ELEMENTS

NLM CDE Repository

Coded NIMHD Common Data Elements

- Labels
- Questions
- Permissible Values

DATA UPLOAD

Acquired **Google and ScHARe Hosted Datasets**

- Overview
- Data Dictionaries
- Data Updates

ScHARe REPOSITORY

Project and Key Acquired Datasets

Overview

Description and Links to Overview Material

4-Privacy Levels

COMMON DATA ELEMENTS

Data

Metadata

Data Dictionaries

Analysis Ready

RAS Single Sign-on

ATO

Common Data Elements + **Data**

Data Access

Based On PII Levels and User Needs:

- Public
- Data Use Agreement
- Private

DATA MAPPING, DOWNLOAD AND EXPORT

Other Cloud Platforms
AnVil, BDC, All of Us

DATA MAPPING

ACROSS DATASETS AND PLATFORMS BASED ON CDES

EXAMPLE: CDE linked

ACS NIMHD Project BioData Catalyst

Aggregated Data Set

CDE Linked Project Data

Data Download in a Variety of Formats

CSV, TSV, XLSX

Data Export to Terra for Analysis

Workspaces

Visualizations Tools

Shiny

ScHARe

Project & federated dataset mapping

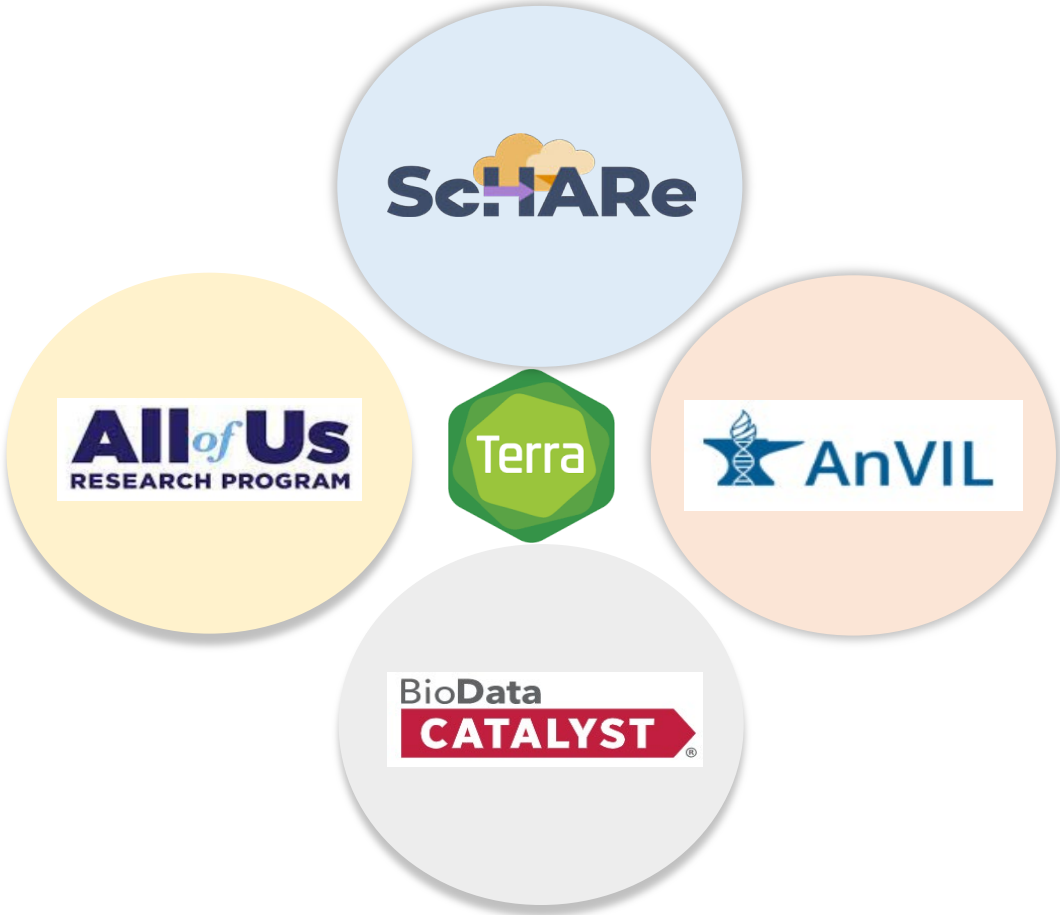
- Project Title
- Project Description
- Core Common Data Elements
- Other Project Data
- Data Dictionary

\+ AMERICAN COMMUNITY SURVEY

\+ Medical Expenditure Survey (MEPS)

\+ Pharmacy and health insurance databases

Mapping across cloud platforms

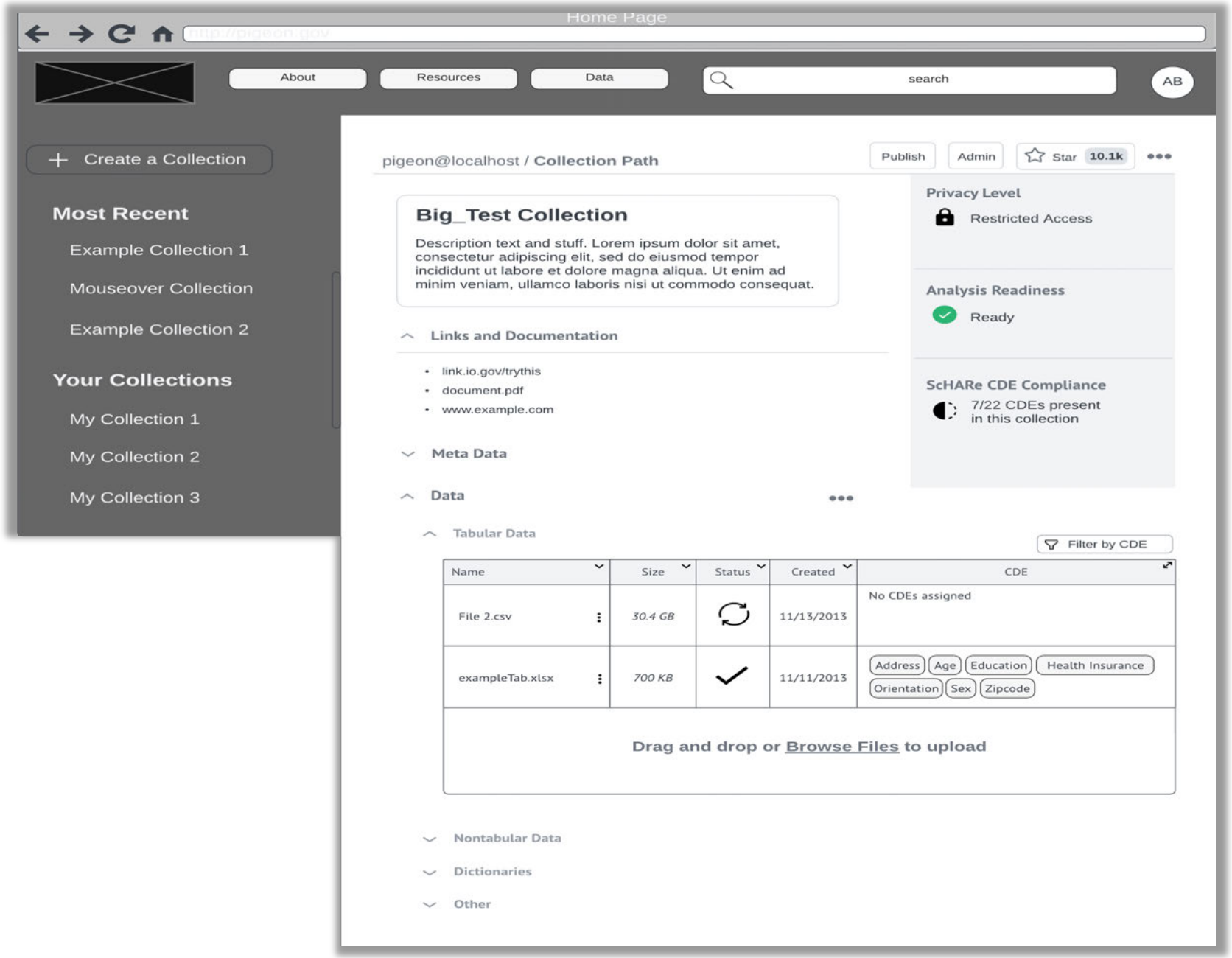


UPCOMING

ScHARe

Repository CDE Focused for Data Interoperability

Coming Soon



ScHARe

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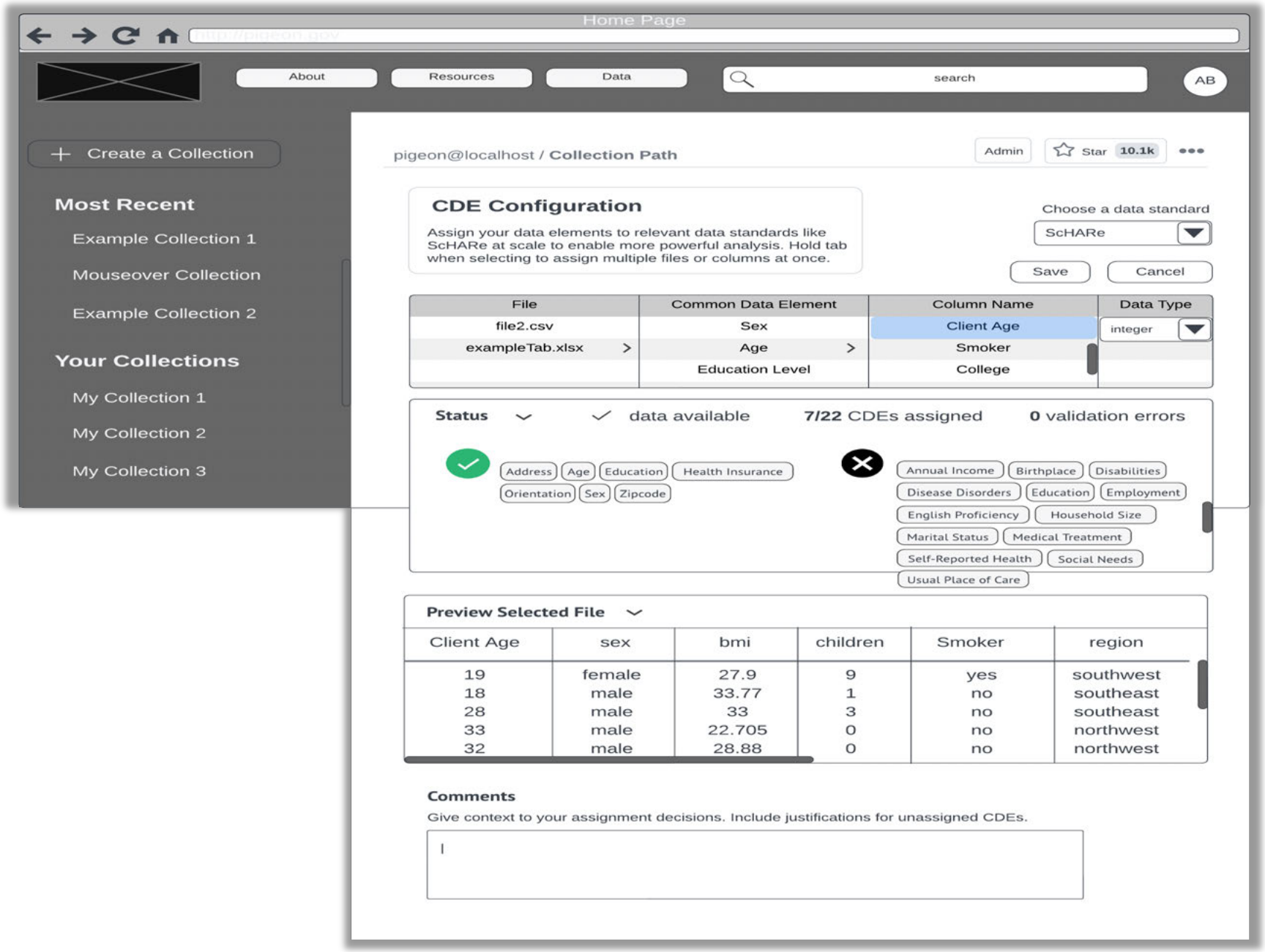
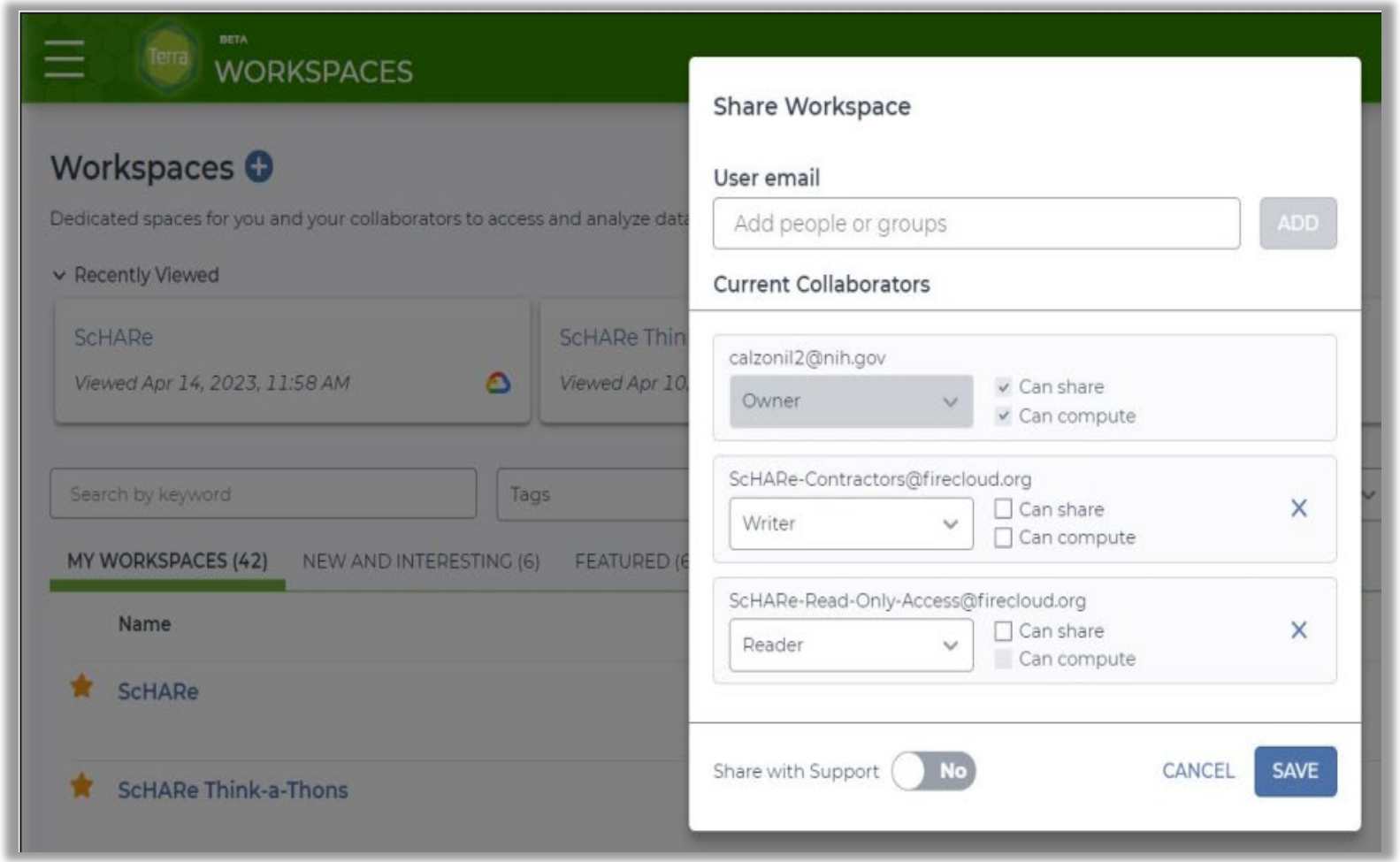
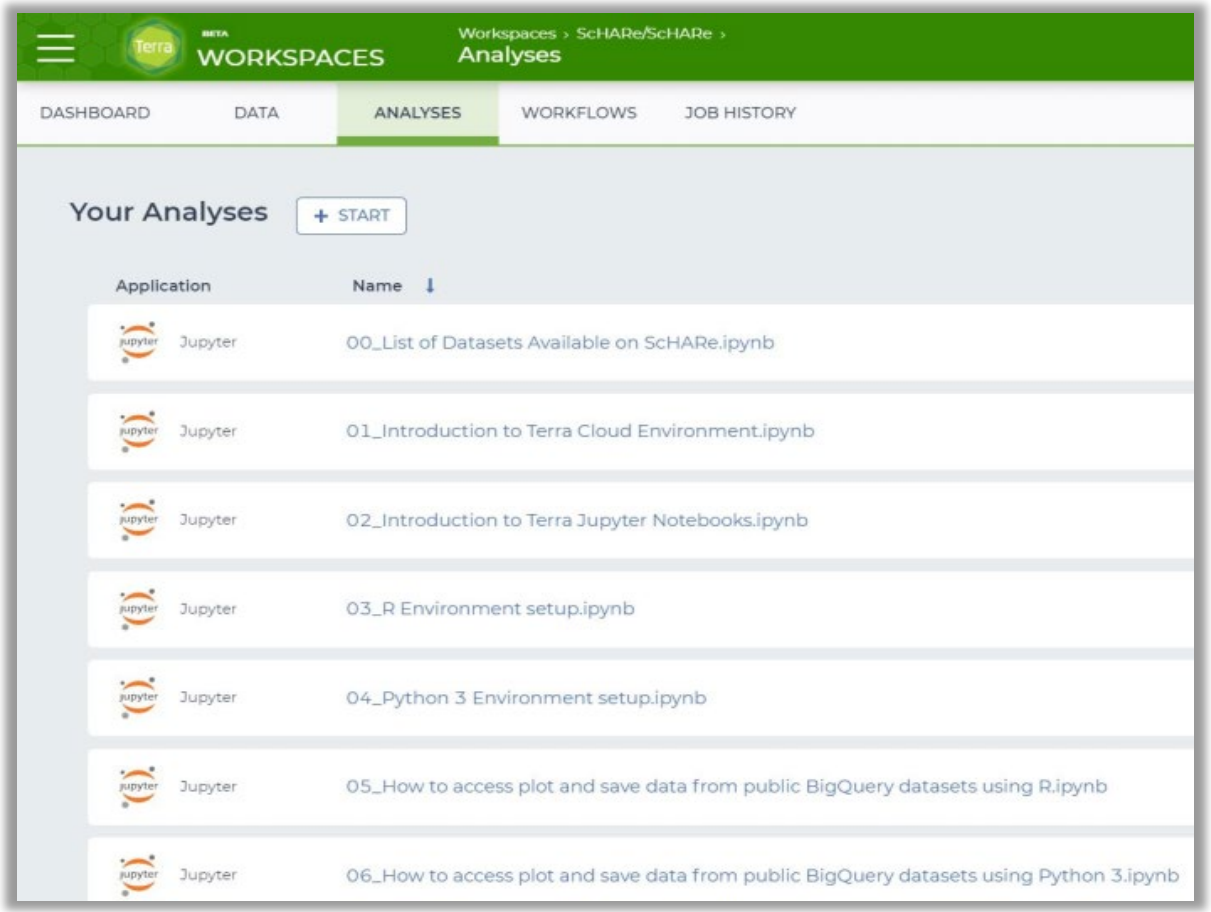


Secure workspace



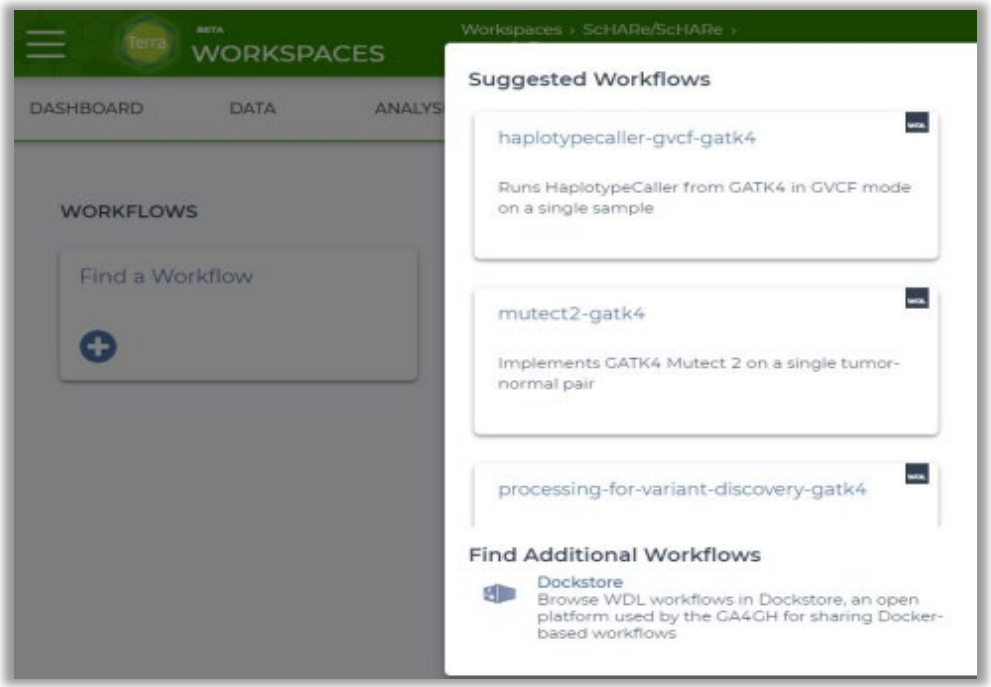
- Secure workspace **for self or collaborative research**
- **Assign roles**: review or admin
- **Host own data and code**

Notebooks analytics



Workflows - Modular codes

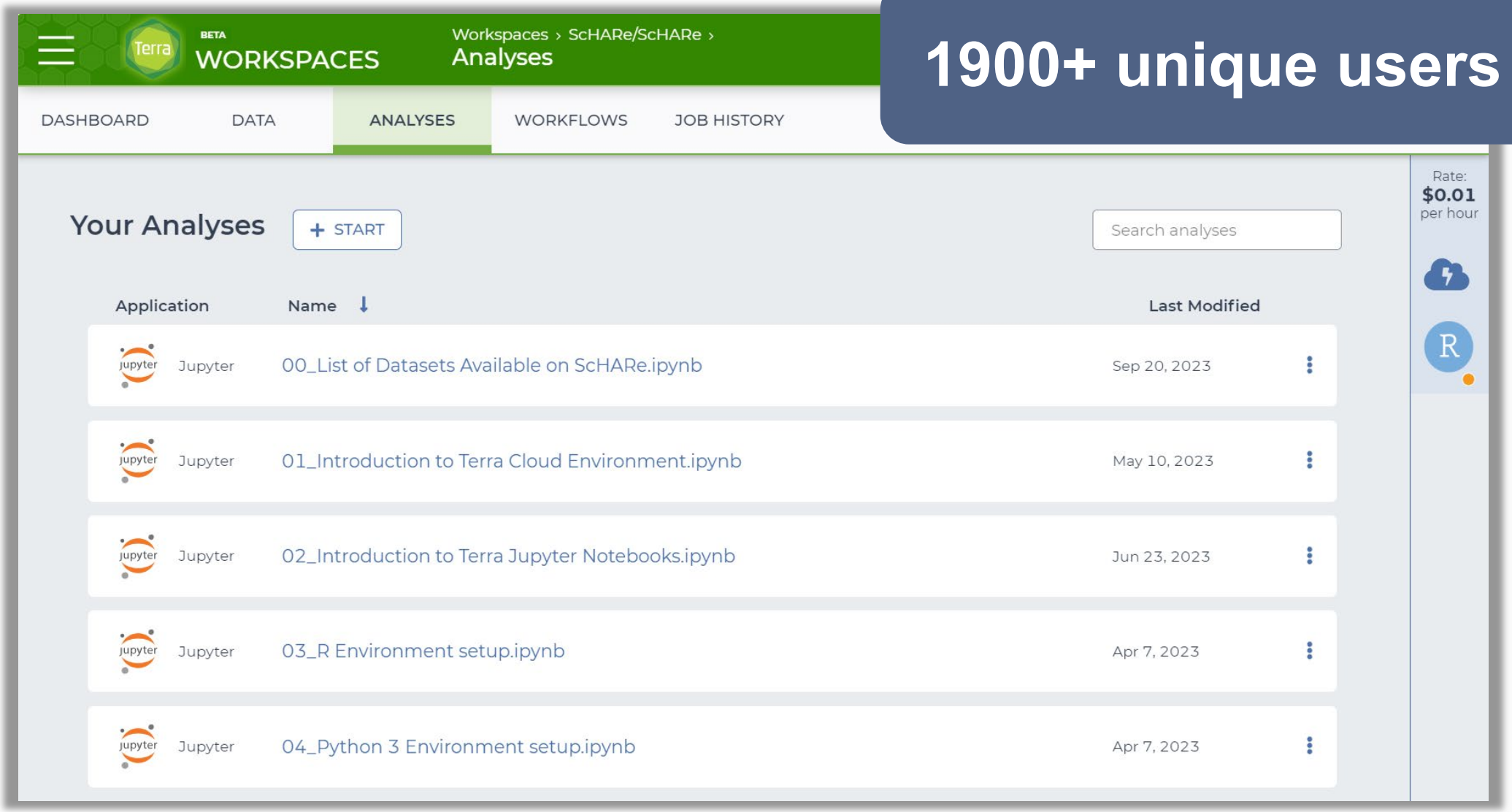
- **Copy and paste analytics**



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

ScHARe Registrations

1900+ unique users



ScHARe

Think-a-Thons

National Institutes of Health

Think-a-Thon Tutorials

February	**Artificial Intelligence and Cloud Computing 101**
March	**ScHARe 1 – Accounts and Workspaces**
April	**ScHARe 2 – Terra Datasets**
May	**ScHARe 3 – Terra Google-hosted Datasets**
	ScHARe for Educators (Community Colleges & Low Resource MSIs)
June	**ScHARe 4 – Terra ScHARe-hosted Datasets**
July	**An Introduction to Python for Data Science – Part 1**
August	**An Introduction to Python for Data Science – Part 2**
	ScHARe for American Indian / Alaska Native Researchers
September	**ScHARe 5: A Review of the ScHARe Platform and Data Ecosystem**
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**
	ScHARe for Coders and Programmers to conduct Research (Jan 31)

bit.ly/think-a-thons

Upcoming

ScHARe

Think-a-Thons (TaT)

Research Teams

Title: Data Science Projects 1 – Health Disparities and Individual SDoH **Description:** Exploring the impact of individual Social Determinants of Health on health outcomes: a hands-on session for researchers and students at all levels interested in collaborating on ScHARe to develop innovative research questions and projects leading to publications.
Title: Data Science Projects 2 - Health Disparities and Structural SDoH **Description:** Assessing the impact of structural Social Determinants of Health on health outcomes: a hands-on session for researchers and students at all levels interested in collaborating on ScHARe to develop innovative research questions and projects leading to publications.
Title: Data Science Projects 3 – Health Outcomes **Description:** Investigating the influence of non-clinical factors on disparities in health care delivery: a hands-on session for researchers and students at all levels interested in collaborating on ScHARe to develop innovative research questions and projects leading to publications.

- Foster a research paradigm shift to use Big Data
- Promote use of Dark Data

- Multi-career (students to sr. investigators)
- Multi-discipline (data scientist & researchers)
- Feature Datasets with Guest Expert Leads
- Secure experts in topic area, analytics, data sources etc. to provide guidance
- Generate research idea - decide potential design, datasets & analytics
- Select co-leads to coordinate completion outside of TaT
- Publications

Register:

bit.ly/think-a-thons

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

Guest expert

Kenneth J. Wilkins, PhD

NIH/NIDDK

About Ken

Ken is a former mathematics and computer science high school teacher who found his way into biostatistics.

He worked for two decades across sectors in biomedical research, and he is now working with both NIH-employed intramural and NIH-funded extramural researchers in his NIH/NIDDK and trans-NIH roles.

His research interests encompass evolving data methods to better suit researchers' posed questions given limitations in data and data-interoperability standards.