

Global Health Epidemiology

Describing burden
of disease and
health states

Determine causes
of disease

Determine risk
factors for disease

Synthesize
evidence

Test
interventions

Make policies
Plan programs

Monitoring
Evaluation



Describing burden
of disease and
health states

Data is Central

to Global Health Work

Determine causes
of disease

Determine risk
factors for disease



Synthesize
evidence

Test
interventions

Monitoring
Evaluation

Make policies
Plan programs

Data Sharing is not yet the norm



The image shows the front cover of a journal article from 'Journal of Clinical Epidemiology'. The cover features the Elsevier logo (a tree) and the journal title 'Journal of Clinical Epidemiology' in bold. Below the title is a subtitle: 'Many researchers were not compliant with their published data sharing statement: a mixed-methods study'. The authors listed are Mirko Gabelica^a, Ružica Bojčić^b, and Livia Puljak^{c,*}. The article type is 'ORIGINAL ARTICLE'. At the bottom, it says 'Accepted 24 May 2022; Published online 30 May 2022'. There is also a 'Check for updates' button.

- 1792 articles indicated that authors were willing to share their data on reasonable request
- 93% either did not respond or declined
- 7% shared data



Data Sharing

is not yet the norm

Original Investigation | Health Policy

Evaluation of Data Sharing After Implementation of the International Committee of Medical Journal Editors Data Sharing Statement Requirement

Valentin Danchev, DPhil; Yan Min, MD; John Borghi, PhD; Mike Baiocchi, PhD; John P. A. Ioannidis, MD, DSc

JAMA Network Open. 2021;4(1):e2033972. doi:10.1001/jamanetworkopen.2020.33972

Key Points

Question What are the rates of declared and actual sharing of clinical trial data after the medical journals' implementation of the International Committee of Medical Journal Editors data sharing statement requirement?

Findings In this cross-sectional study of 487 clinical trials published in *JAMA*, *Lancet*, and *New England Journal of Medicine*, 334 articles (68.6%) declared data sharing. Only 2 (0.6%) individual-participant data sets were actually deidentified and publicly available on a journal website, and among the 89 articles declaring that individual-participant data would be stored in secure repositories, data from only 17 articles were found in the respective repositories as of April 10, 2020.

- 334 articles declared data sharing
- Only 2 (0.6%) datasets were publicly available



FAIR data



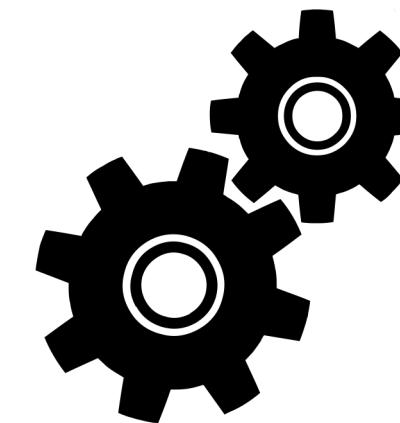
F
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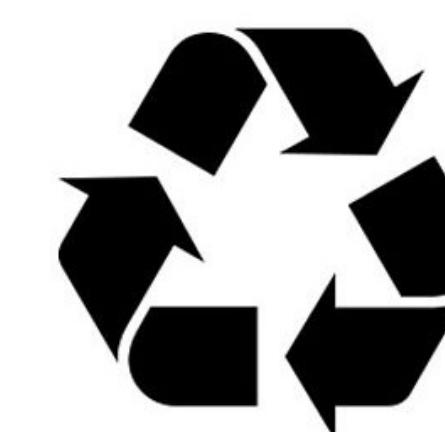
A
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I
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R
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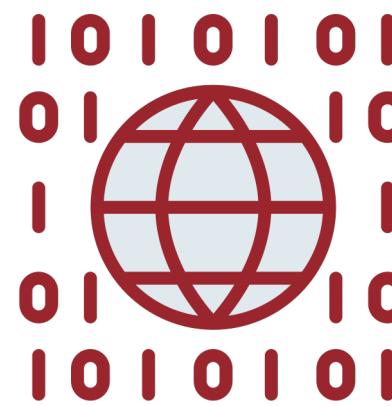


GoFAIR.org

Findable



Data



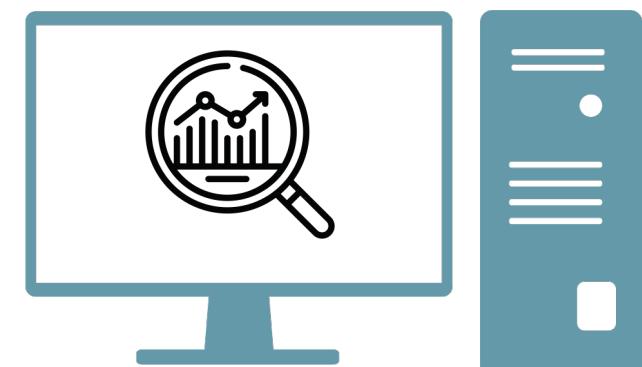
Metadata



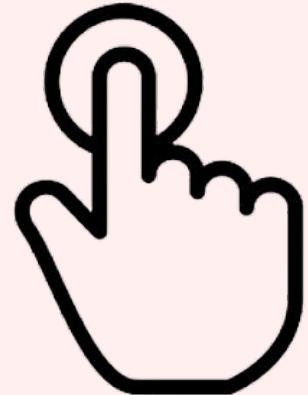
Human-readable



Machine-readable



Accessible



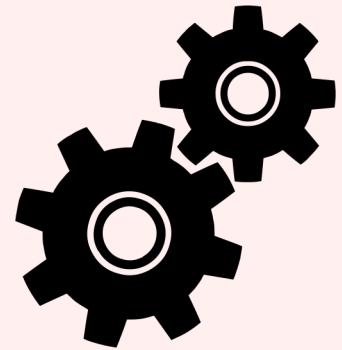
Clear guidance on access



Authentication when necessary



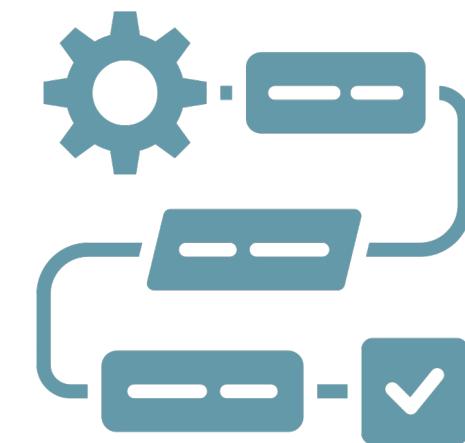
Interoperable



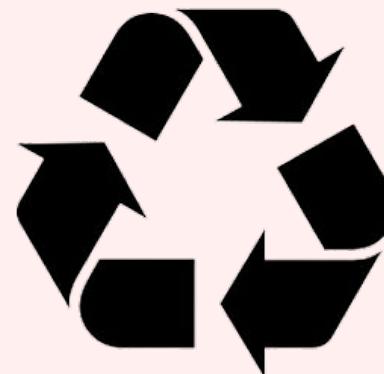
Controlled vocabulary



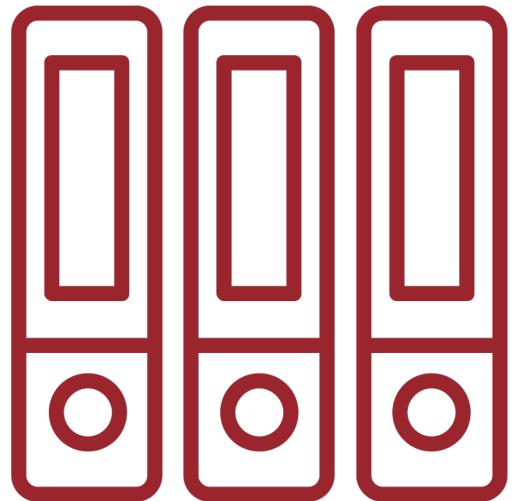
Data works with
applications & workflows



Reusable

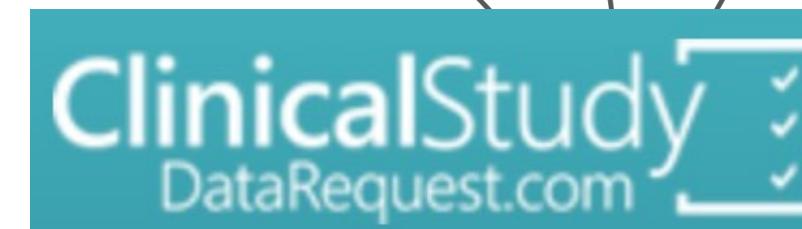


Comprehensive
metadata



Provenance
Origin & processing





Mendeley Data



THE GLOBAL HEALTH OBSERVATORY
Explore a world of health data

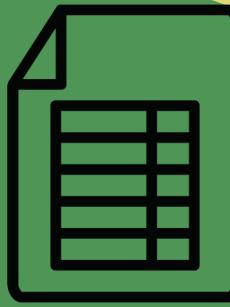
The Data Sharing Landscape



- Government
- Private fdn.
- Industry



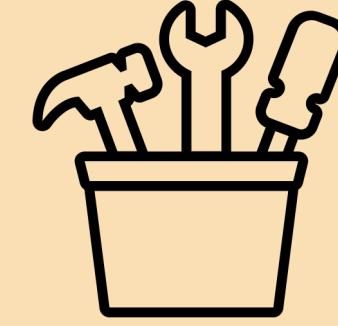
- Generalist
- Specialized domains



- Standardized
- Unstandardized
- Different formats



- Public
- 2 month review
- Tiered access



- Data viz
- Data analysis



75+ STAFF



4+ COUNTRIES



VEuPathDB

Eukaryotic Pathogen, Vector & Host Informatics Resources



CryptoDB

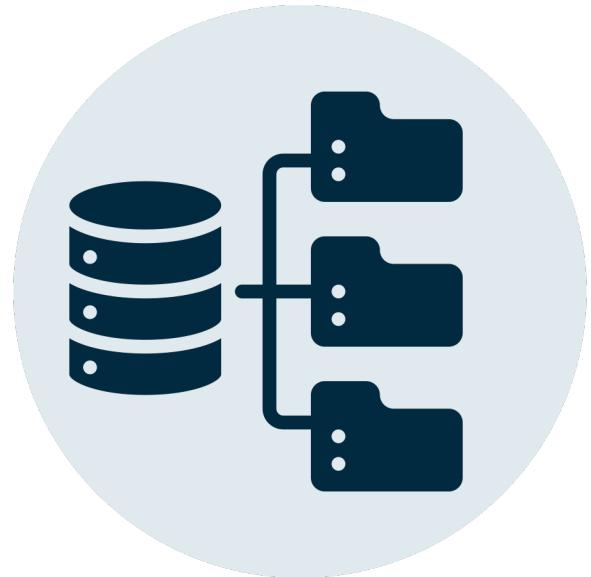
PlasmoDB

VectorBase

ClinEpiDB

What we do

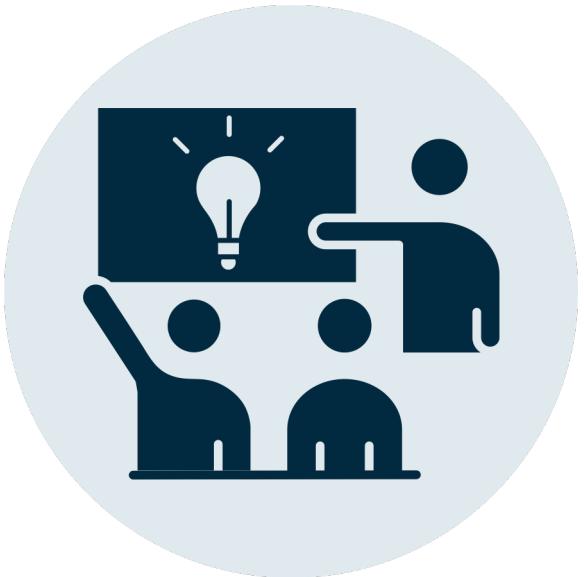
ClinEpiDB provides comprehensive data sharing support to researchers



Database for
clinical & epi data

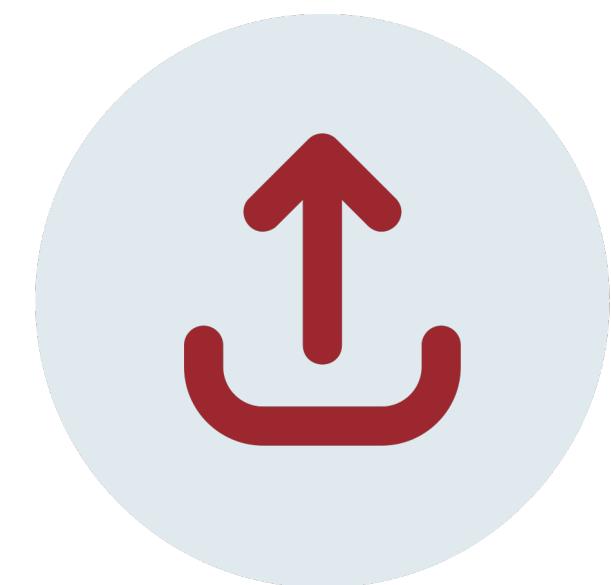


Powerful
data mining tools

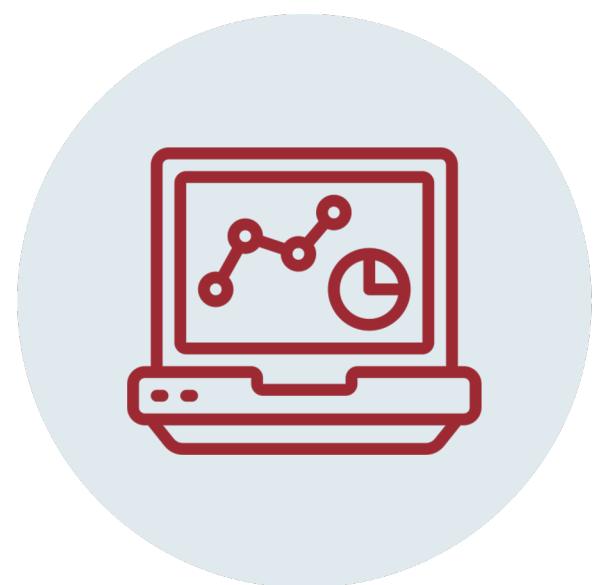


Education
& outreach

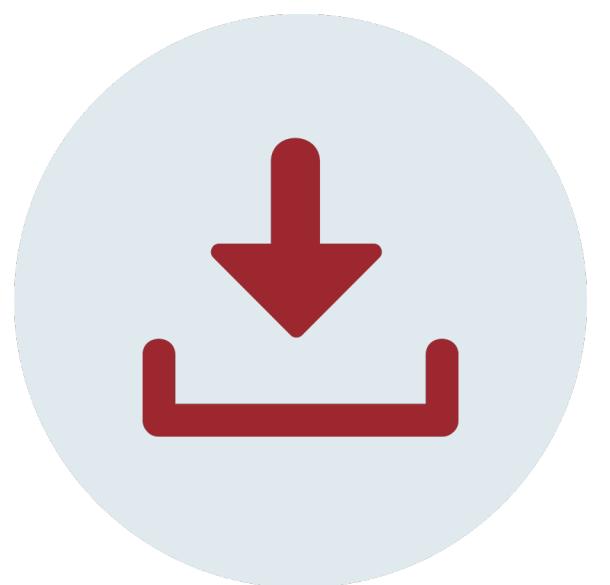
ClinEpiDB empowers researchers to



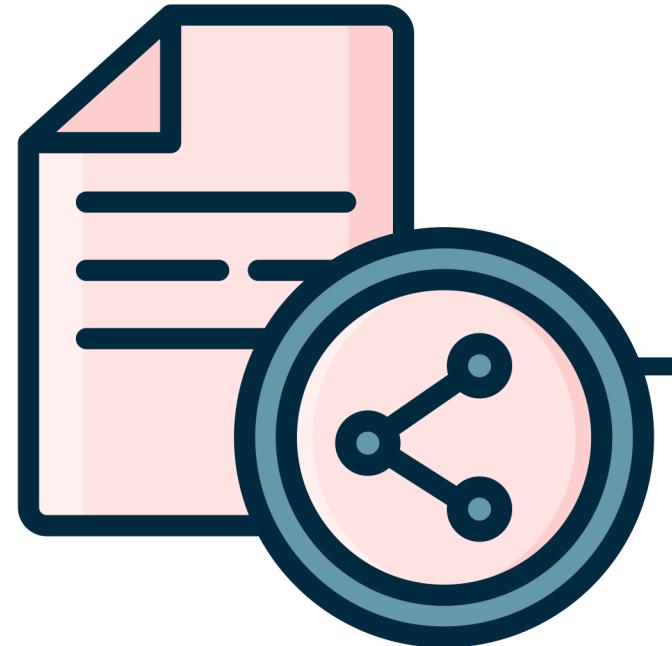
Share their
own data



Explore data
right in the
browser



Use data shared
by others



We promote data sharing

The image shows a laptop screen displaying the ClinEpiDB website (clinepidb.org/ce/app). The website has a dark header with the ClinEpiDB logo and navigation links for Studies, Workspace, Help, About, and Contact Us. Below the header is a banner with the text "Share, explore, and visualize clinical and epidemiological data". A welcome message on the left says "Welcome to ClinEpiDB's new and improved **data exploration platform!** Access the original version of our website, including your saved strategies, at [legacy.clinepidb.org](#)". The main content area is titled "Explore the Studies" and features a "Study summaries table" with three entries:

- Amazonia ICEMR Brazil Cohort** (M)
Study Details [View](#)
6 sites in the Brazilian Amazon, 2010-2014
 - Longitudinal cohort study
 - 640 participants from 194 households with 3186 observations
 - The Amazonia cohort study in Brazil is part of the International Centers of Excellence for Malaria Research (ICEMR) Program
- Amazonia ICEMR Peru Cohort** (M)
Study Details [View](#)
2 Sites in the Peruvian Amazon, 2012-2015
 - Longitudinal cohort with daily recall
 - 2,445 participants from 487 households with 2,050,603 observations
 - The Amazonia cohort study in Peru is part of the International Centers of Excellence for Malaria Research (ICEMR) Program
- ELICIT Randomized Controlled Trial** (M)
Study Details [View](#)
1 Site in Tanzania from 2017-2020
 - 2 x 2 randomized controlled trial with 18 month follow-up
 - 1,084 participants
 - The Early Life Interventions for Childhood Growth and Development in Tanzania (ELICIT) study evaluated the efficacy of

At the bottom of the page, it says "ClinEpiDB Release 22 21 Apr 2022" and "©2022 The VEuPathDB Project Team". There is also a footer with various icons.

Discuss with your neighbor



What are the benefits
of data sharing?



Why would you want
to use data from
other people?

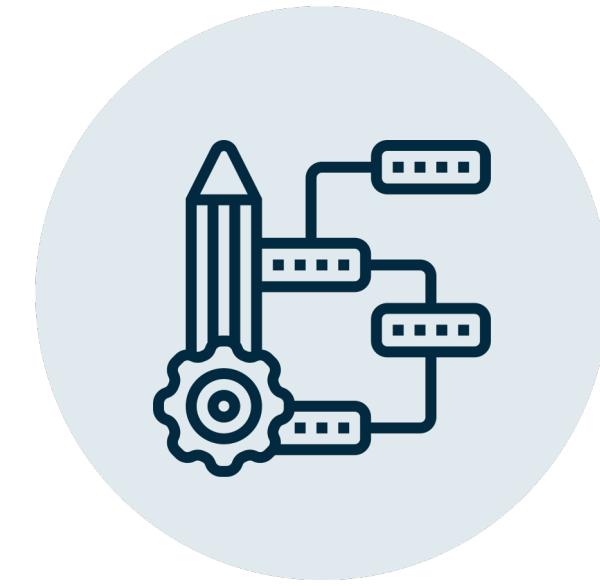
Data sharing benefits the field



Promote
transparency
+ societal trust in
science



Accelerate
discovery

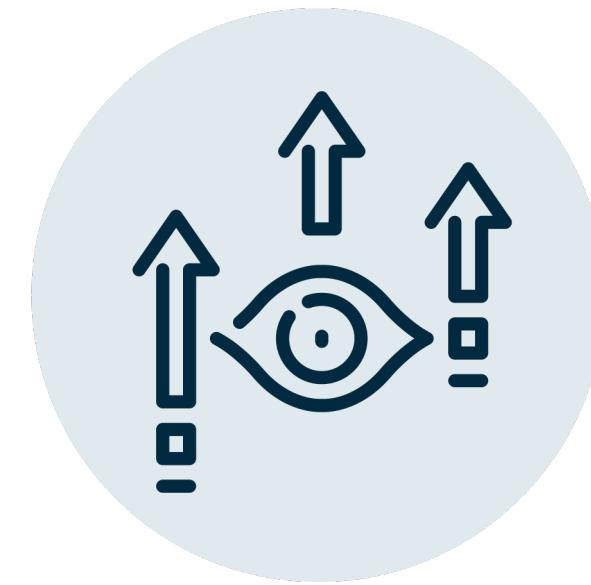


Design better
studies

Data sharing benefits data producers



Foster
collaborations



Visibility
+ Citations

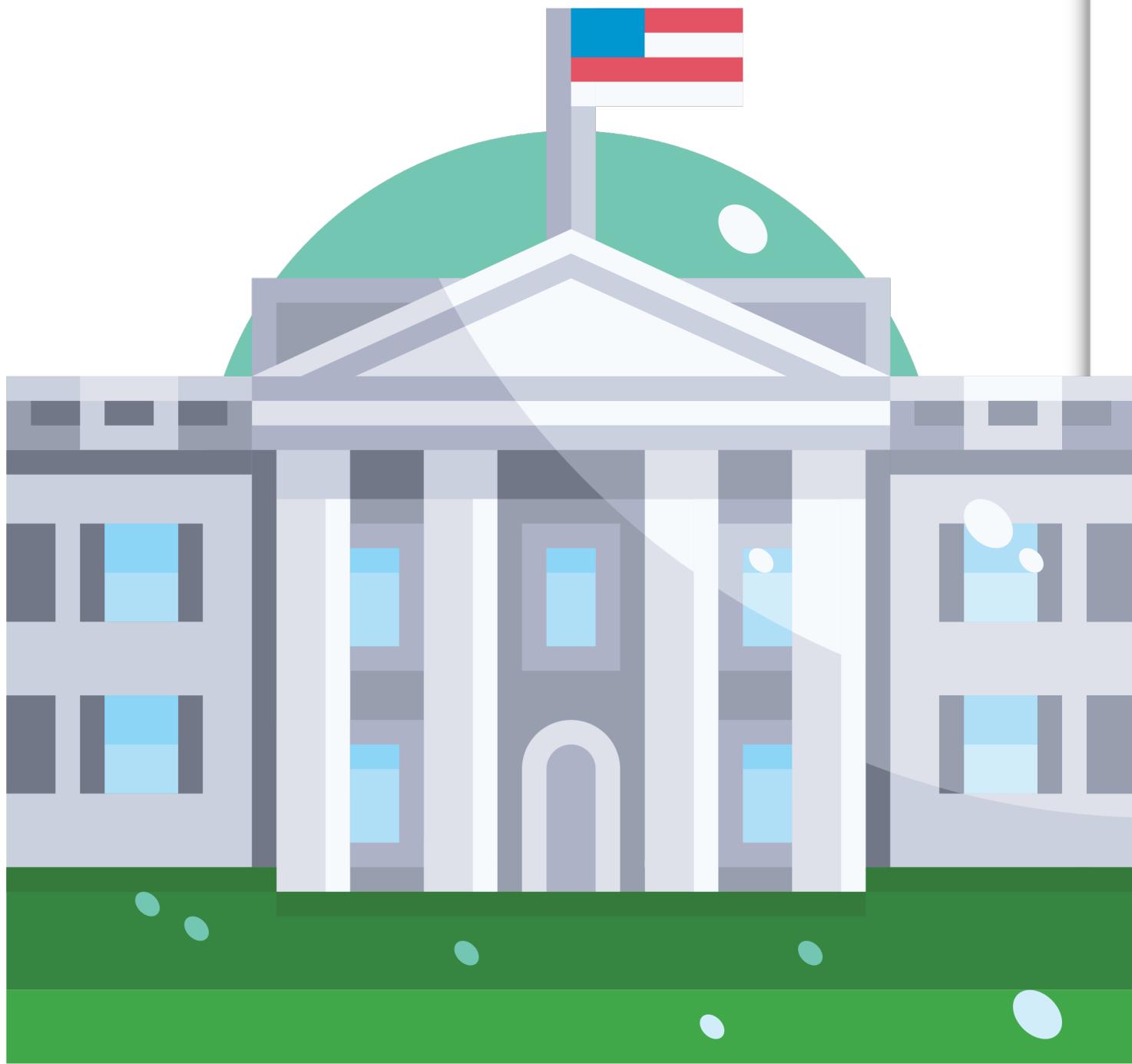
Data sharing is increasingly a requirement



FUNDERS
Preserve research output



JOURNALS
Reproducible research
Transparency



[Administration](#) [Priorities](#) [COVID Plan](#)

AUGUST 25, 2022

OSTP Issues Guidance to Make Federally Funded Research Freely Available Without Delay

Today, the White House Office of Science and Technology Policy (OSTP) updated U.S. policy guidance to make the results of taxpayer-supported research immediately available to the American public at no cost.



National Institutes
of Health

Final NIH Policy for Data Management and Sharing

Notice Number:

NOT-OD-21-013

Key Dates

Release Date:

October 29, 2020

Effective Date:

January 25, 2023



All NIH funded research will require submission of
Data Management & Sharing Plan

- How
- Where
- When

Discuss with your neighbor



What are some challenges with sharing data?



Why do people hesitate to share data?

Data sharing poses challenges



ETHICAL
Participant privacy;
Fairness to data
providers



TECHNICAL
Discoverability;
Lack of data
standards



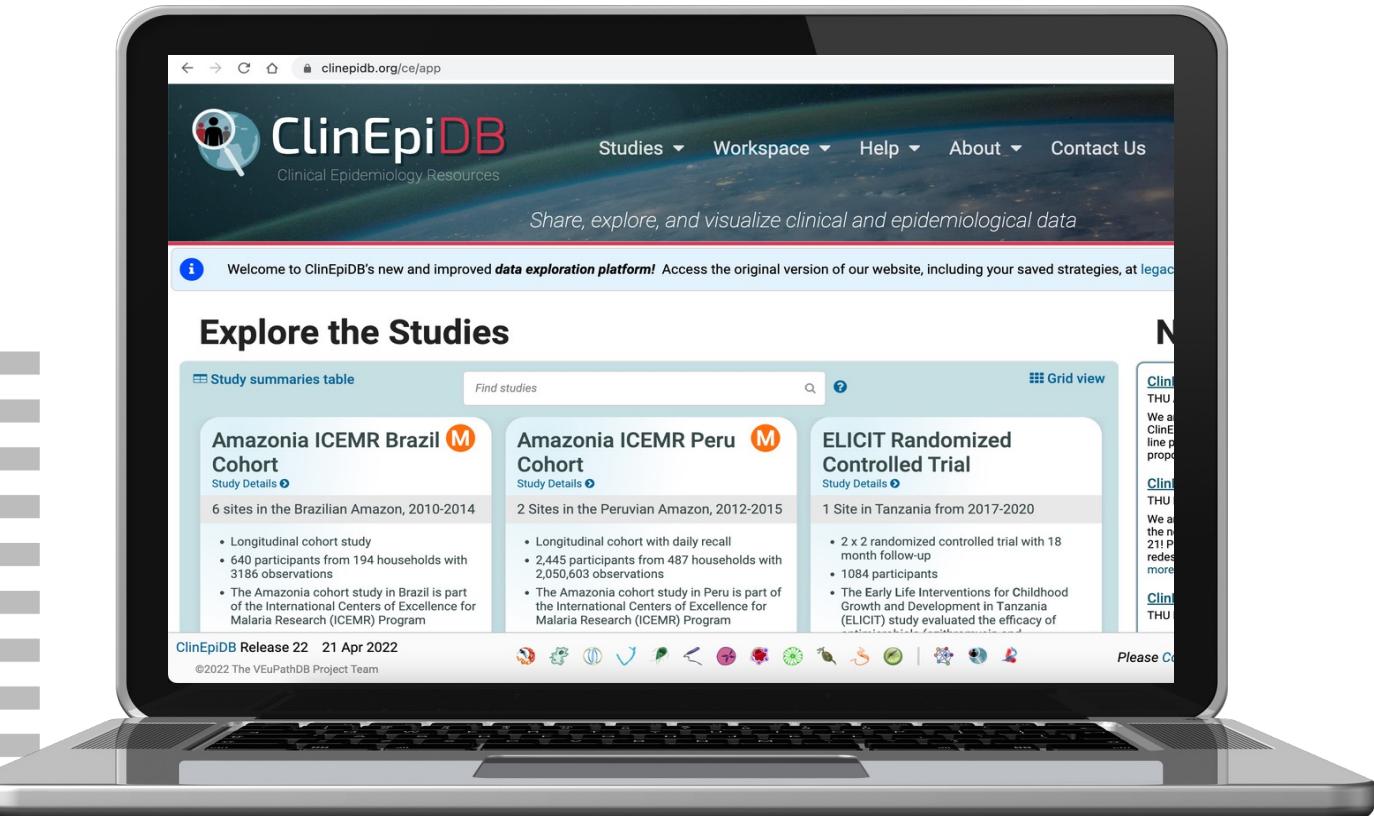
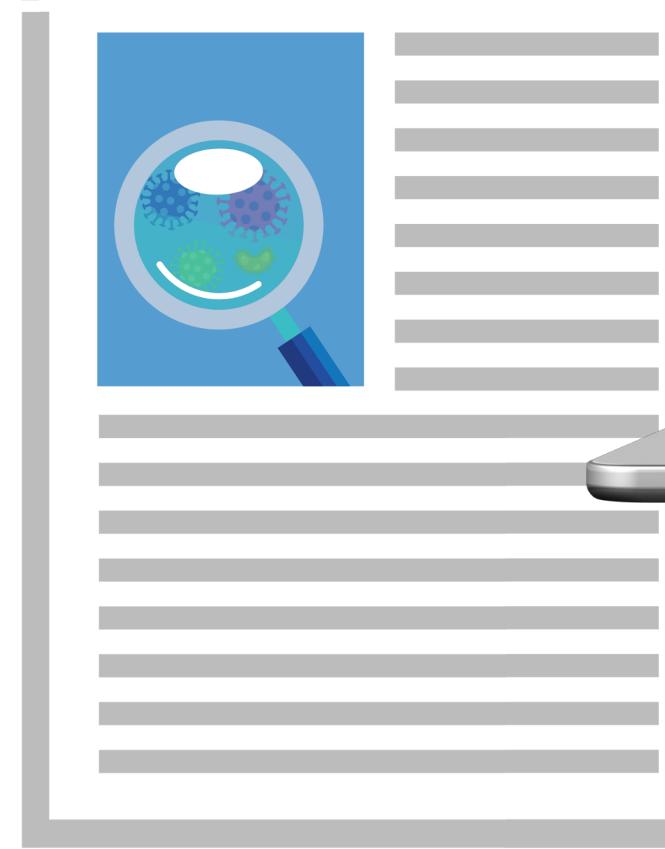
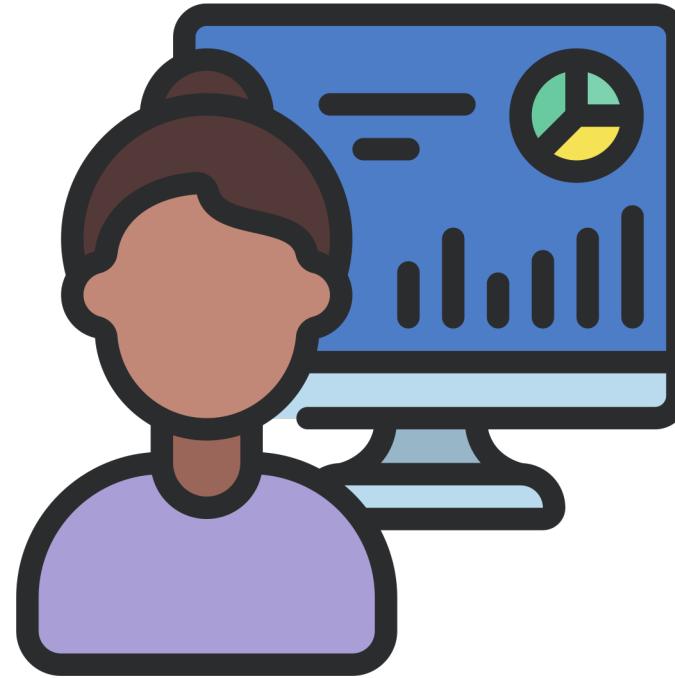
POLITICAL
Lack of trust;
Confusing guidelines



Navigating ClinEpiDB

A screenshot of a laptop displaying the ClinEpiDB website. The website has a dark header with the ClinEpiDB logo and navigation links for Studies, Workspace, Help, About, and Contact Us. Below the header is a sub-header: "Share, explore, and visualize clinical and epidemiological data". A welcome message says: "Welcome to ClinEpiDB's new and improved **data exploration platform!** Access the original version of our website, including your saved strategies, at [legacy.clinepidb.org](#)". The main content area is titled "Explore the Studies" and shows a grid view of study summaries. Three studies are visible: "Amazonia ICEMR Brazil Cohort" (6 sites in the Brazilian Amazon, 2010-2014), "Amazonia ICEMR Peru Cohort" (2 sites in the Peruvian Amazon, 2012-2015), and "ELICIT Randomized Controlled Trial" (1 site in Tanzania from 2017-2020). Each study summary includes a "Study Details" link and a brief description of its characteristics. At the bottom of the page, it says "ClinEpiDB Release 22 21 Apr 2022" and "©2022 The VEuPathDB Project Team".





Meta-analysis and Systematic review- A study of studies