

Data COUNTS™

Collect Data Once, Use Numerous Times

Strengthening the foundations of real-world evidence through
secure, reusable high quality health data

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What is Data COUNTS (At-A-Glance)

Data COUNTS™ (Collect Data Once, Use Numerous Times) is a federal initiative that enables faster, higher-quality use of real-world health data while reducing the collection burden on healthcare systems. Data COUNTS deploys modern data technologies at healthcare partner organizations to extract and de-identify electronic health record data once, while preserving full data provenance and lineage, such that the data is securely reusable for multiple research and public health purposes.

Data COUNTS healthcare partner organizations have full control and oversight over data COUNTS processes at their site. If they choose to do so, they can share de-identified (Safe Harbor) data with the federal government based on their interest. Data is aggregated within a Trusted Data Broker for quality assessments and to engage healthcare partners in data improvement options. The Trusted Data Broker is currently hosted by the Foundation for the National Institutes of Health (FNIH).

Data COUNTS data is shared with the research community through NIH's Controlled Access Data Repositories that are able to share real-world data. Examples include [the National Clinical Cohort Collaborative](#), the [NCI Clinical and Translational Data Commons](#), and the [All of Us Research Program](#). Researchers can request data through the Data Access process within these NIH repositories and data governance follows NIH policies for controlled access data.

The initiative supports biomedical research, disease surveillance, regulatory science, and population health by enabling rapid, reproducible access to high-fidelity data through a trusted, privacy-preserving architecture.

Why Does Data COUNTS matter?

The U.S. government and healthcare systems currently collect similar data multiple times for different programs, creating unnecessary cost, delay, and burden on health systems.

Data COUNTS addresses this challenge by:



Reducing repetitive and costly data extraction efforts



Improving data quality, completeness, and transparency



Preserving full data lineage and provenance



Accelerating time to research insights and decision-making



Enabling a health learning system



Supporting secure data sharing with rigorous privacy protections



Creating a single agreement to onboard health systems to share data with various enclaves and end users

By collecting data once and using it many times, Data COUNTS helps transform fragmented health data into a reusable national resource.

What Data COUNTS enables?

Data COUNTS enables:

Rapid, reproducible research using real-world data across multiple institutions

Secure, privacy-preserving data sharing through de-identification within a zero-trust infrastructure

High-fidelity data reuse with full provenance for downstream corrections and validation

Faster cohort identification and analysis, often in weeks instead of months

Support for diverse use cases, including cancer surveillance, chronic disease research, post-market safety monitoring, and population health studies

A foundation for a learning health system, where insights are fed back to improve care, research, and policy

Who Participates

Data COUNTS is a collaborative initiative that brings together partners across the health data ecosystem, including:



Healthcare systems including academic medical centers, community hospitals, and integrated delivery systems



NIH Institutes, Centers, and Offices, with input from federal partners including FDA, CDC, CMS, and ASTP/ ONC



Research partners supporting real-world evidence and biomedical discovery



Trusted technology partners that support secure data infrastructure and analytics



Patient, professional, and community organizations focused on improving health outcomes and empowering patients

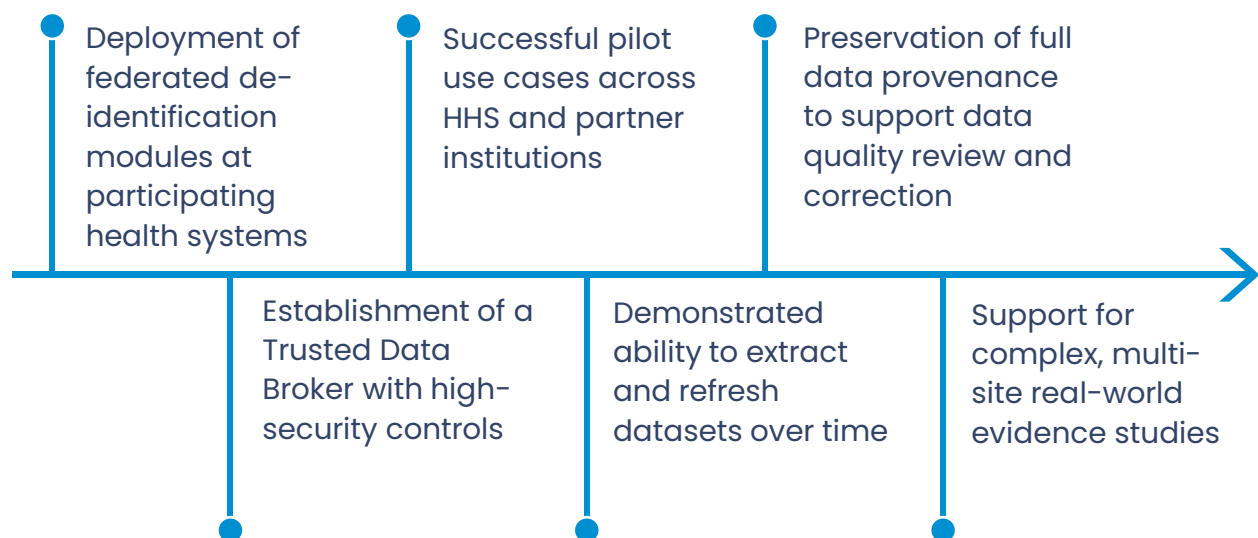


Public and private partnerships interested in advancing the use of RWD

Current and prospective participants include institutions contributing data for cancer surveillance, chronic disease research, real-world effectiveness studies, and population health initiatives, with a long-term vision to expand participation to community clinics, federally qualified health centers, and diverse care settings.

Key Milestones/Features

Data COUNTS has demonstrated early progress and continues to expand capabilities, including:



These milestones establish Data COUNTS as a scalable foundation for future health data reuse.

Governance & Security

Data COUNTS is designed with rigorous governance, privacy, and security protections at its core. Key safeguards include:

HIPAA Safe Harbor de-identification performed by provider organizations

Zero-trust data architecture

Full audit logging and transaction tracking

Role-based and use-case-specific data access controls

Institutional Review Board oversight for approved use cases

Alignment with federal security standards, including FISMA and FedRAMP requirements

These protections ensure that data is used responsibly, transparently, and in accordance with applicable policies.

Participating Institutions

**Ann & Robert H. Lurie Children's
Hospital of Chicago**

 **Ann & Robert H. Lurie
Children's Hospital of Chicago®**

Baylor College of Medicine



**Community Clinic of Northwest
Arkansas FQHC (CCNWA)**



Ohio State University



North Dakota University



Sanford Health



**Tampa General Hospital & USF
Health**



**University Hospitals Cleveland
Ohio**



University of California Irvine



University of Chicago Medicine



University of Kentucky



University of Nebraska Medical
Center



MD Anderson



Are you interested in learning more or participating in Data COUNTS?

Healthcare organizations, researchers, and partners are invited to explore how Data COUNTS can support secure, efficient use of real-world health data while reducing data collection burden.

For more information, updates, or partnership inquiries, please contact the Data COUNTS team datacounts@nih.gov or visit the program website.