CTSA Clinical & Translational ®
Science Awards

CTSA Program Informatics Common Metric: *Enhancing collaboration and opportunities for discovery through interoperable data*

How does Informatics help us realize the vision of the CTSA Program?

The CTSA Program is growing to become a collaborative and interoperable national research network that can leverage resources across multiple information systems and apply unique expertise within our institutions to connect research to health care, resulting in better health through research.

Why an Informatics Common Metric?

Informatics provides critical tools, methods and resources to accelerate translational research. The forthcoming Informatics Common Metric aims to improve discovery opportunities within and among CTSA Program hubs through metrics that encourage data repository quality and harmonization across hubs.

What data will we be required to report?

Hubs will be asked to provide data about their local repository such as the total number of unique patients and prevalence of standardized domain-specific data to describe the quantity and comparability of data in the local repository.

Specific Goals of the Informatics Common Metric

- Facilitate the interoperability of research data models through standards-based data repositories.
- Facilitate sharing of the repository's assets for discovery.
- Encourage use of standards-based data models, not bound to a specific technology, but harmonized with other organizations, agencies, and initiatives (i.e., PCORI, ONC, FDA, and the Trial Innovation Network).
- The long-term goal is machine-readable, interoperable data that adhere to the FAIR data principles.

What is 'FAIR' data?

- ✓ **Findable:** data are assigned a globally unique and eternally persistent identifier.
- ✓ **Accessible:** data are retrievable by their identifier using a standardized communications protocol.
- ✓ **Interoperable:** data use vocabularies that follow FAIR principles.
- ✓ **Re-usable:** data have a plurality of accurate and relevant attributes.

How does Informatics support data interoperability in the CTSA Program?

Data Standards: compatible research systems and use of standard terminologies to enable data harmonization
Data Integration: integrating different types of data from different sources for discovery and improved health
Data Access & Data Sharing: ability to query across sources and organizations and respond to diverse queries; enable data access, integration, and processing
Data Quality: ensure data are fit for purpose, provide benchmarking for new tools and algorithms
Data Security: user friendly infrastructure to assist investigators in ensuring the security of their data

New opportunities for strategic management for your hub and for the CTSA Program Consortium

A consensus baseline value will reflect a minimal set of clinical research data for each CTSA Program hub, enabling comparisons and identifications of synergies and gaps across the CTSA Program. This metric will provide continuous improvement for the CTSA Program and hubs by:

1. Enhancing interoperability by broadening the range of standardized data types in a hub's data repository
   - ✓ Data types include demographics, diagnoses, labs, medications, procedures, etc.
2. Offering each hub opportunities for strategic management of their data repository
   - ✓ Enabling comparisons with other institutions thereby facilitating prioritization of repository expansion

Tentative Timeline

- Summer 2017: Development and testing of the metric in collaboration with the Informatics Domain Task Force
- Late Summer 2017: Pilot the metric
- Late Fall 2017: Metric finalized and introduced to CTSA Program hubs
- Ongoing: communication and support for hub Common Metric Implementation Teams

Frequently Asked Questions:

What is Informatics?

The study and practice of creating, storing, finding, manipulating and sharing information. The American Medical Informatics Association (AMIA) indicates that "Informatics is the intersection between the work of stakeholders across the health and healthcare delivery system who seek to improve outcomes, lower costs, increase safety and promote the use of high-quality services."

What is a Data Repository?

A data repository (for the purposes of the CTSA Program) is a structured collection of clinical and/or research data available to investigators for research at a CTSA Program's primary institution.

What is the rationale for the informatics Common Metric to focus on data repositories?

In order to accelerate translation, researchers need access to a broad range of previously collected data (electronic health records, omics, imaging, genetics, behavioral, etc.). These data can come from different sources such as clinical databases, research datasets, sensors, mobile technology, social media, patient generated data and publicly available data sets. The sharing and pooling of data across CTSA Program hubs requires that data be represented in a format that may be queried and adheres to commonly accepted standards.

What is the current state and existing challenges with data repositories in the CTSA Program hubs?

- Lack of harmonization with costly support of multiple research models (PCORI, Sentinel, OMOP)
- Lack of semantic and syntactical consistency across the CTSA Program Consortium
- Deep phenotyping and other aspirational research activities are limited by data models, limited data elements, and a lack of quality control
- Lack of ability to engage and support parallel initiatives such as Accrual to Clinical Trials (ACT) Network, that are focused on cohort discovery

What is FAIR data?

FAIR is a set of guiding principles to make data **Findable, Accessible, Interoperable, and Re-usable** to optimize data for use by humans and machines. Learn more at the FORCE11 FAIR Data Principles website and the FAIR Principles Working Detailed Document.
- Findable: data are assigned a globally unique and eternally persistent identifier.
- Accessible: data are retrievable by their identifier using a standardized communications protocol.
- Interoperable: data use vocabularies that follow FAIR principles.
- Re-usable: data have a plurality of accurate and relevant attributes.

Where can I learn more about the Common Metrics and how data collection, reporting, and strategic management have been accomplished from previous metrics?

Please visit the Common Metrics Initiative website:
- Common Metrics FAQs
- Implementation and Training Materials
- Clear Impact Scorecard Information
- Common Metrics Collaborative Learning Sessions

I have questions and suggestions – who can I contact?

Questions and suggestions can be emailed to: Erica Rosemond, PhD at Erica.Rosemond@nih.gov.