Informatics Overview and Team Formation Tool

What is Informatics?
- Informatics is the study and practice of creating, storing, finding, manipulating and sharing information, with focus on the systems used for same. (Databases, electronic medical records, clinical data sets, etc.)

What is the rationale for having an Informatics Common Metric (ICM)?
- To accelerate translation, researchers need access to a broad range of data from different sources that can be harmonized, often referred to as being interoperable.
- The sharing and pooling of data within and across CTSA Program hubs requires that data be represented in a format that adheres to commonly accepted standards, and can therefore be queried.
- To achieve this data harmonization, it is necessary to know what types of data are being collected, managed, and stored in each hub’s clinical research data repository, and how much of these data are in the standard formats.
- Standard formats allow for a query written by any site to be run across data from clinical research data repositories of different hubs.
- The Informatics Common Metric (ICM) provides an assessment of the consistent use of standard formats in selected domains (e.g. age, laboratory values) at each hub. Over time, the number of domains included in the ICM will increase.
- The purpose of the ICM is to: 1) identify clinical research data gaps at each hub that limit cross-CTSA interoperability; 2) stimulate efforts to address these gaps, and; 3) to improve overall CTSA network capacity to efficiently use clinical research data.

Goal of Informatics for the CTSA Program:

Improve the interoperability of data within multiple systems by making the data adhere to the FAIR data principles to ultimately enable rich, machine-readable data:

Findable: the data are assigned a globally unique and eternally persistent identifier

Accessible: the data are retrievable by the identifier using a standardized communications protocol

Interoperable: the data use vocabularies that follow FAIR principles

Reusable: the data have a plurality of accurate and relevant attributes
Informatics Common Metric Team Formation Tool

Purpose
The following provides guidance on building the optimal CM Informatics Team for your hub. The recommendations are based on post pilot survey data provided by the 16 hubs that piloted the Informatics Common Metric (ICM). Questions were specific to the processes used to form their ICM teams.

Overall, hub feedback indicated that effective teams included a mix of content experts in Informatics, and others who have experience in evaluation and using Results Based Accountability for development of the strategic management Turn the Curve plans. Lastly, at least one team member requires technical expertise in the use of the Clear Impact Scorecard software.

Areas of Expertise:

Pilot hubs reported the roles and expertise of staff selected for the ICM teams. A majority of the hubs selected staff with expertise in the following areas:

- Evaluation
- Informatics
- Information Technology (IT)
- Data Analysis
- Senior Administration

Evaluation: Several hubs stated that individuals with expertise in evaluation were selected or volunteered to participate in the ICM team because they were already involved in data collection, and reporting for the existing Common Metrics. Many had familiarity with developing Turn the Curve plans. Other hubs reported that evaluation staff traditionally take a leading role for all Common Metrics and this metric was no different.

Informatics: Many of the hubs had existing Informatics programs, or functions within or external to their CTSI. Team formation started within these existing groups, with individuals selected based on their institutional roles. At other hubs, the existing Common Metrics core team queried the

Best Practices for Team Formation:

Use a mix of individuals with content expertise, familiarity with Common Metrics, experience in RBA, and the Clear Impact Scorecard system.

Train staff not previously trained in Results Based Accountability.

Include individuals with expertise in:

- Evaluation
- Informatics
- IT
- Data Analysis
- Senior Administration

Engage team members to build ownership, interpret results, develop and implement strategies/next steps, manage deliverables and timelines, and monitor progress.

Use script resources from the GitHub site, including updates provided by the ICM Development Team and other hubs.
Informatics group to identify someone to participate, and then that individual identified additional potential team members with specific data model contacts and expertise.

**IT:** Hubs selected individuals with specific domain expertise, including Chief Information Officers, software architects, data repository directors, developers, and those tasked to manage the core data at the hubs, based on their first hand/working knowledge of the data model(s) used at the hubs.

**Data Analysis:** Hubs selected data integration managers, data analysts, and other data officers with operational knowledge of the underlying data populating the data model(s). Several hubs leveraged existing collaborations between Informatics groups and data analytic staff.

**Senior Administration:** Half of the pilot hubs included senior management in their hub teams. For some this was a standard practice with all Common Metrics projects. Others indicated that it was helpful to have senior management staff to provide leadership and oversight, as well as to facilitate inter-departmental cooperation. This may be particularly useful if the clinical data warehouses and related informatics expertise reside outside of the hub.

**Engaging the ICM Team:**

Many hubs indicated that the effort to engage individuals to be members of the ICM team was minimal; that there was a keen willingness to engage based on familiarity with the Common Metrics Initiative, or with the metric’s goals. Other hubs identified the following strategies to engage the members of the ICM team. Principal Investigators at some hubs worked to build buy in to the metric’s goals as a way to engage the ICM team members. Several hubs indicated that meeting early on with the team (i.e. prior to the availability of data) to discuss processes, deliverables, and timelines was helpful. A majority of hubs indicated that multiple meetings were essential for team cohesion and to establish and maintain forward momentum. One hub indicated that they invited all members to attend the CLIC Common Metric web conferences, to serve as a common point of reference for the project, stating that the CLIC web conferences and the report-out also served as a forcing function to facilitate the team’s work toward completing the pilot.

**Working with the Scripts Provided on GitHub:**

While some editing of the scripts was needed, a majority of hubs indicated that the edits took one person, one day to complete, and that the editing was accomplished by members of the ICM Pilot team. A few hubs did not include individuals with data model expertise on their team. In those cases, assistance in running or modifying the script was sought from individuals with expertise. When engaging persons with data model expertise, hubs should take into account time demands and competing commitments, as these may delay the availability of results.
Results Based Accountability/Scorecard Familiarity:

As depicted in the table, hubs were asked what proportion of staff members on the ICM Pilot team completed, or had previously completed training in Results Based Accountability (RBA).

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Hubs with a greater proportion of staff trained in RBA indicated that it was “Somewhat Easy” to “Very Easy” to develop the components of the Turn the Curve plan (Story Behind the Curve, Partners, Strategies, What Works, and Actions). Several hubs did indicate that engaging in additional RBA training would have been helpful. This may be especially true for those who were content experts in other areas.

Each hub has at least two individuals with access to the Clear Impact Scorecard system. While these individuals were viewed as essential to the ICM Pilot team, if the persons with Scorecard access were not trained in Informatics, some extra coordination was necessary to complete the Turn the Curve planning processes. To address this gap, hubs convened meetings to explain the different sections of the Turn the Curve Plan, what their purpose was, what type of information typically is included, and providing examples from other Common Metrics the hubs had completed.