CIBMTR Data Transformation is Here!
What Data Managers Need to Know

TCT: CRP/Data Manager Meeting 2021
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2/4/21
Disclosures

Disclosure Information:

No financial interest or conflict of interest
Learning Objectives

1. What is meant by ‘Data Transformation’ at CIBMTR?
2. What was last year’s pilot and was it a success?
3. What is happening this year with the initiative?
4. How does the data move?
5. What will be different in how I submit data to CIBMTR under the new model?
6. How can my center get involved?
Data Transformation: Brief Overview
Q: What is Data Transformation:

A:
1. Putting data into storage for records retention archiving and auditing purposes.
2. Reimagining how data can be collected, submitted, analyzed and shared.
3. A new technology regulation from the Office of the National Controller (ONC) for data governance requiring CIBMTR compliance.
4. A method of transforming data into billable units for reimbursement purposes.
Vision

Optimize the acquisition and utilization of CIBMTR’s entrusted data assets to accelerate breakthroughs that transform patient experiences.
CIBMTR Reimagined through Data Transformation

**Source**: Target Modular Data Collection (Electronic Data Capture)

- High Quality
- Timely
- Interoperable

**Learning Knowledge Cycle**

**Impact Assessment**: Clinical Quality, Cost/Affordability, Patient Satisfaction

**Translation**: Clinical Practice, Health Policy, HIT

**Research Studies**

**Data Science**

**Algorithm Development, Machine Learning/AI**

**Hypothesis Generation**

**Authentication Driven/Open Access Data Ecosystem**

- Molecular
- SES
- PROs...

**Data Enrichment**: Link with new data sources

- Source Code Repository
- Data Enclaves for Analysis
- Data Dictionary
- Tooling
- Metadata Informatics

**DOTS**

- Equal Outcomes for All
- Best Practices
- Equal Access
- EFS

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Paradigm Changes

Current

- Data is developed via question responses
- Hardwired platform, system dependencies dictate process
- Interpreted data
- Document centric collection sequential approach
- Submission rests on transplant centers / administrative burden
- Downstream data validation/reactive

Future

- Data is born interoperable and digital
- Updates and modifications are seamless to centers supplying data
- Sourced data
- Data-level acquisition triggered once populated or with a new value for push
- Distributed burden granting permission to care delivery vendors to submit data
- Upstream data validation – automated/ more proactive
Y1 Pilot Activities and Results
## Our First Partners

<table>
<thead>
<tr>
<th>Site</th>
<th>Transmission Method</th>
<th>Data Exchanged</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Ohio State University</td>
<td>CIBMTR Reporting App</td>
<td>V 0.3 data</td>
</tr>
<tr>
<td>Children’s Hospital of Colorado</td>
<td>CIBMTR Reporting App</td>
<td>V 0.3 data</td>
</tr>
<tr>
<td>Oregon Health and Science University</td>
<td>CIBMTR Reporting App</td>
<td>V 0.3 data</td>
</tr>
<tr>
<td>Sarah Cannon Research Institute (Medical City Dallas)</td>
<td>SFTP</td>
<td>CRID Assignment</td>
</tr>
<tr>
<td>Moffitt Cancer Center</td>
<td>HML Gateway</td>
<td>HLA</td>
</tr>
<tr>
<td>Duke University</td>
<td>CIBMTR Reporting App</td>
<td>V 0.3 data</td>
</tr>
</tbody>
</table>
## Y1 Scope

<table>
<thead>
<tr>
<th>Key Activities</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collect Raw Data</td>
<td>X</td>
</tr>
<tr>
<td>• types defined by transmission method</td>
<td></td>
</tr>
<tr>
<td>• from center’s ‘source of truth’</td>
<td></td>
</tr>
<tr>
<td>Move test data into a CIBMTR lower environment for transmission testing purposes</td>
<td>X</td>
</tr>
<tr>
<td>Move actual raw data to CIBMTR production environment</td>
<td>X</td>
</tr>
<tr>
<td>Validate the raw data is consistent with the data fields requested from the ‘source of truth’</td>
<td>X</td>
</tr>
</tbody>
</table>
## Pilot Evaluation: Stakeholder = Center’s

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Focus</th>
<th>Performance Measure</th>
<th>Process Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Decrease administrative burden</strong> in the reduction of time spent in submitting data to the CIBMTR (includes data collection and transmission)</td>
<td>Prototype performance: automation decreased time for this previously manual process.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Participation by centers from a resource perspective would be limited to site-specific tasks only therefore <strong>minimally disruptive</strong>.</td>
<td>Minimally disruptive for center participation at resource level.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td><strong>No new technical requirements</strong>, met the data where it is at/sourced.</td>
<td>Minimally disruptive for center at technical level.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Concept as implemented is an <strong>improvement from current state</strong> and data acquisition model</td>
<td>Radically better than current model and should be continued.</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
The Results are IN

<table>
<thead>
<tr>
<th>Key Performance Indicator</th>
<th>Satisfied</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Viable prototype that is feasible to scale, high performing</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Minimally disruptive for site to participate</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Project management on time and on budget</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Reduced administrative burden</td>
<td>✔️</td>
<td>Partial data currently</td>
</tr>
<tr>
<td>Data latency improved and delay of data receipt reduced</td>
<td></td>
<td>Favorable but not enough data to fully evaluate during pilot</td>
</tr>
<tr>
<td>Data accuracy improved due to automation vs manual error potential</td>
<td></td>
<td>Favorable but not enough data to fully evaluate during pilot</td>
</tr>
</tbody>
</table>
Y2 Activities
2021: Data Acquisition Part II

Move more data! Add more partners!
Technology 101

How does this all work?
The Challenge – Can Automation be Applied?

Find and collect raw data

Move raw data to the CIBMTR
Guiding Principles

– Automate
– Meet the data where it resides
  • EMR
  • Research database
  • LIMS system
  • OMOP database or CDM
– Put the center in control of all aspects
– Enlist technical standards and data standards wherever possible
– CIBMTR performs data conversions for center if needed.
## Moving Data - Transmission Methods

<table>
<thead>
<tr>
<th>Secure File Transfer Process (SFTP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HML Gateway (File Uploader)</td>
</tr>
<tr>
<td>CIBMTR Reporting App</td>
</tr>
<tr>
<td>Direct FHIR</td>
</tr>
</tbody>
</table>
Moving Data – A Few Questions First…..
## Moving Data – Center Specific Determination

### Where is my data stored?

<table>
<thead>
<tr>
<th>Menu Selection</th>
<th>Center’s Data Source of Truth Location</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Research Database</td>
</tr>
<tr>
<td></td>
<td>LIMS</td>
</tr>
<tr>
<td></td>
<td>Epic EMR</td>
</tr>
<tr>
<td></td>
<td>Other EMR</td>
</tr>
<tr>
<td></td>
<td>BMT software program repository</td>
</tr>
<tr>
<td></td>
<td>Observational Medical Outcomes Partnership (OMOP)</td>
</tr>
<tr>
<td></td>
<td>Common Data Model (CDM) repository</td>
</tr>
</tbody>
</table>
What data does my center want to send?

<table>
<thead>
<tr>
<th>Menu Selection</th>
<th>Data Types</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HLA Data from Form 2005</td>
</tr>
<tr>
<td></td>
<td>Clinical Care Observational Data</td>
</tr>
</tbody>
</table>
## Moving Data - Transmission Method Selection

<table>
<thead>
<tr>
<th>Method</th>
<th>Center’s Data Source of Truth Location</th>
<th>Data Categories</th>
<th>Initial Effort</th>
</tr>
</thead>
<tbody>
<tr>
<td>HML Gateway (File Uploader)</td>
<td>LIMS</td>
<td>HLA (Form 2005)</td>
<td>Develop code from CIBMTR data specs to put into HML format</td>
</tr>
<tr>
<td>CIBMTR Reporting App</td>
<td>Epic EMR</td>
<td>Clinical Observational Mapped Data</td>
<td>App configuration only</td>
</tr>
</tbody>
</table>

### Highest Value Experienced

- CIBMTR Reporting App
- Epic EMR
- Clinical Observational Mapped Data
## Evolving the CIBMTR Reporting App

<table>
<thead>
<tr>
<th>Version</th>
<th>Released</th>
<th>Functionality</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>v0.1</td>
<td>May 2019</td>
<td>• Patient Demographic Data Exchange</td>
<td>• FName, LName, DOB, Gender</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• CRID Verification Y/N</td>
<td>• Per Epic aGVHD flow sheet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• aGVHD Observation display</td>
<td></td>
</tr>
<tr>
<td>v0.2</td>
<td>August 2019</td>
<td>• Patient Demographic Data Exchange</td>
<td>• E2E processing in FN3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• CRID Assignment</td>
<td>• Returns CRID via UI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• aGVHD Observation display &amp; exchange</td>
<td></td>
</tr>
<tr>
<td>v0.3</td>
<td>September 2020</td>
<td>• Patient Demographic Data Exchange</td>
<td>• Race and ethnicity added</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Laboratory results display &amp; exchange</td>
<td>• Found on #2402</td>
</tr>
<tr>
<td>v0.4</td>
<td>September 2021</td>
<td>• Priority data variables (n= ~120) across entire FN3 library</td>
<td>• Collected by DOS for reference point if data variable is repeated across forms</td>
</tr>
</tbody>
</table>
### Moving Data - Transmission Method Selection

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<td>Clinical Observational Data</td>
<td>Develop code from CIBMTR data specs</td>
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<td>Direct FHIR</td>
<td>Research Database or other Data Repository</td>
<td>Clinical Observational Data</td>
<td>Develop code CIBMTR data specs</td>
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**Alternate Options**
True or False?

FN3 will be retired because all the data collected in FN3 today will soon be sourced and moved electronically?

FALSE
Data Variables 101

How will CIBMTR reconcile data collected electronically vs. data I enter onto the Forms?
Data Falling into Place from the Patient Journey

Electronic Data + FN3 Data = Complete Patient Picture
Making Sense of the Data Variables

FN3 is based on Patient Journey Snapshots….

Context is built into the forms in FN3 to trigger:

– Sections for different diseases
– Questions at different timepoints
Making Sense of the Data Variables

FN3 Data Capture

Electronic Data Capture

- 2012-05-09
  HEMATOCRIT 42.1 %

- 2012-02-03
  HEMATOCRIT 41.5 %

- 2010-04-29
  HEMATOCRIT 42.5 %
Making Sense of the Data Variables

**Problem:**
Ambiguous data received electronically needs a human to provide contextual clues.

**Current Solution:**
Data Managers will provide the contextual data on the forms 2400 and 2402 in FN3

**Result**
Logic is applied to use the contextual data input to pre-populate data variables across forms.
Data Manager Experience
Decides the viewable collected electronically data is:
- appropriate to the patient
- accurate
- ready to send

Decide by:
- data variable
- or all collected variables by patient CRID

Authorize PUSH to CIBMTR
Submitting contextual data in FN3

Data manager needs to complete the 2400 and submit the first two questions on 2402

– Data manager leaves the 2402 in SVD status
– Information from 2400 and 2402 is used to derive the correct labs received electronically to populate the lab questions on 2402 form
Population of lab data on 2402

Data manager returns to the 2402 and lab questions will have answers.
 Partners Wanted
What questions will be asked?

There are multiple pathways available for sharing data with DTI depending on where site data is stored, what standards are used, and what transmission options are available.

**What data types are accessible for transmission?**
- Demographics
- Labs
- Performance / progression
- Acute GvHD
- Treatments
- Procedures
- HLA

**Where is the data stored, and how difficult to access?**
- Epic EMR
- Cerner EMR
- Separate LIMS system
- Research database
- OMOP database

**What file formats and transmission approaches are already supported?**
- FHIR (e.g., via CIBMTR Reporting app or direct)
- SFTP
- XML / JSON
- HML

**Which vocabularies are in use?**
- ICD-10
- SNOMED
- LOINC
- RxNORM
Who can my center contact to get started?

Bridget Wakaruk:
Sr. Relationship Manager/ Innovation

Email: dt@nmdp.org
But wait…. I have more questions

CIBMTR.org/ data management/ data transformation

CIBMTR Data Transformation

DT1 Pilot Deemed a Success, Looks to Expand to New Network Partners (10.22.2020)

There isn’t an exact roadmap to follow—this has never been done before—but what is being done is necessary to save lives and help patients thrive after transplant. Bringing data together in a timely manner accelerates research to reveal new insights and transcend scientific frontiers.

Pilot prototype testing now complete

The CIBMTR has relied on a web-based model of data collection using an extensive library of forms that are filled out at intervals across a transplant patient’s lifespan. Under a new model, the team has successfully brought together healthcare data standards that enable research network partners to collect and send data from their source data systems efficiently and securely. This new model, using a prototyped set of solutions, is both future-proof and sustainable because it meets the data where it resides and allows data to become interoperable.

For more information on this and other news, visit CIBMTR.org/data.