What can you do with CIBMTR data?

J. Douglas Rizzo, MD MS
February 27, 2014
Overview

• CIBMTR Accomplishments 2013
• What is CIBMTR doing with data?
• What data is available to centers
  – Where is it?
• Cool future projects
CIBMTR Accomplishments 2013

• Center Outcomes Report 2013
• Center Volumes Report
• Use of data in studies
• Unrelated and related donor-recipient repository
• QOL pilot study
Center Volumes Report

• Data reflecting centers’ HCT volumes for 2008 - 2012 reported to CIBMTR
• Posted online and available using query tools Dec 2013
• One utility/publication of data from SCTOD to the .gov website
Program Website
Center Outcomes Report
Final study population - 2013

- Centers must have >90% overall f/u at 1 year
  - One center excluded in 2013 for incomplete reporting of allogeneic HCT
- 168 centers; 19,958 patients first allo HCT
- Primary outcome: One year survival
  - Overall: 65.7% (71% REL, 62% UNR)
- Center outcomes report 2013 includes 3 full years of data:
  - Unrelated and Related HCT 2009 – 2011
Center Outcomes Report 2013

- 3 year rolling time window
- Outcome: 1 year survival
- Multivariate analysis adjusts for ‘risk factors’
- Full data on HCT Comorbidity Index (Sorror, et al)
- Reports for 2013 sent to centers Jan 2014
  - Additional univariate descriptive reports for centers accompany report
- Reports available on web Jan 2014
  - http://bethematch.org/access
- Reports sent directly to payers Jan 2014
How are we doing?

Risk Adjusted Performance

- Above Expected
- As Expected (79%)
- Below Expected (13%)

N = 168
Donor-Recipient Specimen Repository 2013

• Unrelated Donor Repository
  – 28,625 AdultRecipient/Donor pairs
  – 2,658 Recipient/Cord pairs
  – 11,657 samples distributed to investigators during 2013

• Related Donor Repository
  – 52 centers participated in 2013
  – 2,495 Adult Recipient/Donor pairs

• More than 1.6 million aliquots stored
CIBMTR studies
Peer-reviewed Publications, 2004-2013
Observational Research Studies

- >1,600 researchers participate in WCs
- 102 proposals submitted, 62 presented, and 43 accepted for the 2013 WC meetings
- 156 proposals submitted for the 2014 WC meetings
- 65 ongoing collaborative studies with numerous organizations, including international and US-based hospitals, research centers, universities, and registries
QOL Project

- Pilot project within SCTOD to collect QOL data from recipients
  - Assess direct CIBMTR patient contact with minimal center burden
- 8 centers participating
- Accrual Aug 2011 – October 1, 2013
  - 390 patients
    - 249 Adult/67 Pediatric
- Ongoing follow-up through 1 year
What data is available from CIBMTR?
And how can you get it?

- DBtC
- CIBMTR websites
- Information requests
- AGNIS
- Other tools
Data Back to Centers (DBtC) – What is it?

Web-based application, deployed on the CIBMTR Portal as a core solution to securely share with domestic and international transplants centers their own center-specific Transplant Essential Data (TED) which have been further validated and processed into the CIBMTR Observational Database.
Data Back to Center (DBtC) version 1.5

Welcome to the Data Back to Center (DBtC) web application!

The DBtC application provides Transplant Centers with the ability to retrieve data submitted to the CIBMTR. DBtC currently provides FormsNet and IBMTR (pre-December 2007) TED level data. These data can be exported in comma-separated value (CSV) format.

Data Last Updated: December 2013

The preTED and postTED Data Dictionary and Code Definitions documents have been revised into one comprehensive Excel formatted document. We hope that this new format will be easier to use. A ‘Center Tip Sheet’ has also been added with the most common Excel functions used by centers to manipulate the data.

The current pre and post TED Data Dictionaries utilize questions numbers associated with version 2 of the TED forms. The form version 3 has no content difference from version 2; it is only the electronic equivalent. Data from the recently released forms version 4 is not expected to be available until 2014. The data
DBtC – CIBMTR Portal

DBtC Data Download

Choose your CIBMTR Center Number (CCN):  10000

PreTED, IBMTR Legacy Registration and Pre-TED Equivalent Data (Form 2400):
PostTED, IBMTR Legacy Registration and Post-TED Equivalent Data (Form 2450):

Get CSV
Get CSV
DBtC - Audience

• Available to all staff that are ‘authorized’ personnel at their center and have registered for a username and password through the CIBMTR Portal.

• DBtC is intended to be used by medical directors, IT staff, and center investigators for a variety of tasks including center based reporting, analysis, and research.
DBtC – Current State

• Datasets updated on a quarterly basis.
• DBtC can be accessed 24/7.
• Includes FormsNet and legacy IBMTR data (pre-December 2007).
• TED and TED level equivalent data are available for both allogeneic and autologous transplants.
• Two international registries use this portal to receive these data for participating centers
  – CBMTG
  – APBMT
DBtC – Latest enhancements

• Updated version of data dictionaries & FAQs were released on the Portal.
• Data dictionaries and code definition tables now provided in Excel, rather than PDF format.
• Additional ‘Tips for Centers’ document is now available on the Portal.
• Removed time stamps from date fields in downloads.
DBtC – Data Usage

Unique centers that downloaded data

- 2011: 80
- 2012: 85
- 2013: 122

CIT Overview – Data Sharing (DBtC)
DBtC – What’s next

• Upgrades to support new Form Revisions.
• Increasing the frequency of updating the datasets from quarterly to monthly.
• Consideration has been given to provide more comprehensive data.
• Feedback on enhancements to be collected throughout the BMT Tandem Meetings for consideration/analysis.
Other Information Resources

>450,000 page views in 2013
Information Resources

• Summary slides, survival statistics
• Publication list with Pubmed abstract
  – Lay summaries for recent selected publications
• Center outcomes forum summaries and analysis methodology
• Links to center volume query tools, center outcomes results on other sites
# Information Services

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>573</td>
<td>410</td>
<td>429</td>
<td>412</td>
</tr>
<tr>
<td>Pharmaceutical Company</td>
<td>180</td>
<td>114</td>
<td>61</td>
<td>59</td>
</tr>
<tr>
<td>Patient or Relative</td>
<td>7</td>
<td>9</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>Patient Advocacy Org</td>
<td>45</td>
<td>30</td>
<td>45</td>
<td>33</td>
</tr>
<tr>
<td>Market Research Firm</td>
<td>19</td>
<td>22</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>Government Agency</td>
<td>14</td>
<td>15</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Insurance Company</td>
<td>8</td>
<td>11</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Medical Society</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Student</td>
<td>3</td>
<td>4</td>
<td>21</td>
<td>16</td>
</tr>
<tr>
<td>News Media</td>
<td>1</td>
<td>8</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Law Firm</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cord Blood Bank</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>855</strong></td>
<td><strong>627</strong></td>
<td><strong>583</strong></td>
<td><strong>567</strong></td>
</tr>
</tbody>
</table>
What is coming?

• One year survival calculator based upon center specific survival analysis

• Why?
  – Provides valuable prognostic information for MDs, useful for consent conferences.

• How to access:
  – CIBMTR portal for authorized user access
    • initially center directors
  – Limitations based upon complexity of tool and knowledge required to use it, designed for specific need of transplant MDs
What is coming?

![Patient One Year Survival Probability Calculator](image)

**Patient One Year Survival Probability Calculator**

**Recipient Characteristics**
- Recipient Age: 30 to 39
- Recipient Gender: Male
- Recipient Race/Ethnicity: Caucasian
- Recipient CMV Status: Negative
- Karnofsky/Lansky Score at Transplant: Greater than or equal to 90
- HCT-CI Comorbidity Score: 1

**Disease Characteristics**
- Disease: Hodgkin's Lymphoma
- Resistance to chemotherapy (HL only): Sensitive

**Transplant Characteristics**
- Prior Autologous Transplant: No
- Conditioning Intensity (NHL, HL, PCD, CLL and Solid Tumors only): Myeloablative
- Graft Type: PBSC

**Donor Characteristics**
- Donor Type/HLA: URD 8/8
- Donor Age (URD BM or PBSC only): 31-40
- Donor Gender (BM or PBSC only): Male

***All fields are required!***

**Predicted Patient One Year Survival Probability Estimate:** 83%
Data sharing through AGNIS?

- What data is available through AGNIS
  - Any data in previously curated forms
- Who can access it?
  - Vendors (StemSoft, Remedy, etc)
  - Centers (though challenging!)
  - Interested registries
    - Canadian Blood and Marrow Transplant Group
  - Future REDcap connectivity
AGNIS 2013

• EBMT-CIBMTR and CIBMTR-Eurocord AGNIS connections in progress – EBMT has submitted 7200 CRID forms and is submitting pre-TED, 100 day post-TED and infusion information for those HCT.
• Data elements for CIBMTR forms are in NCI caDSR library
• Supports submission of 15 forms (next page):
  – Over 13,000 form submittals with AGNIS
  – 4 centers making direct submittals
  – 1 registry supporting 50 centers
  – 6 vendors certified for production submittal
• Form retrieval:
  – 2 centers doing direct retrieval
  – 2 vendors supporting center retrieval
AGNIS Supported Forms

- Form 2000 - Recipient Baseline Data
- Form 2004 - Infectious Disease Markers
- Form 2005 - Confirmation of HLA Typing
- Form 2006 – HSCT Infusion Form
- Form 2018 - Hodgkin and Non-Hodgkin Lymphoma Pre-HSCT data
- Form 2100 - 100 Days Post-HSCT Follow-up Form
- Form 2118 - Hodgkin and Non-Hodgkin Lymphoma Post-HSCT data
- Form 2200 - Six Months to Two Years Post-HSCT Data
- Form 2300 - Yearly Follow-Up for Greater Than 2 Years Post-HSCT data
- Form 2400 - Pre-Transplant Essential Data
- Form 2450 - Post-Transplant Essential Data
- Form 2451 - Chimerism Studies
- Form 2455 - Selective Post-Transplant Essential Data
- Form 2804 – Unique ID form
- Form 2900 - Recipient Death Data
Publicly Available Data Task Force

• What information and datasets should CIBMTR make available on its websites?
• Broad recommendations regarding:
  – Restructuring data query tool underlying center HCT activity
  – Displays of data on .gov, cibmtr.org, bethematch.org (including center outcomes performance)
  – Datasets to make available
• Deliberations finishing late Spring
What cool stuff is on our horizon?
EMR user group

• Objective is to define CDEs and tools to capture common HCT domains in the EMR
• Build the tools in the EMR with robust CDEs that facilitate point of care data capture as structured data elements that can be easily found in “back end” databases and used for data exchange
• First vendor is Epic
  – Commitment to central build available to any Epic customer
What cool stuff is on our horizon? BRIDG

- Biomedical Research Integrated Domain Group (BRIDG)
- 2,700 data elements defined in caDSR as CDEs (8,000 FN data points)
- 1,300 (5,400 FN data points) CDEs defined in the BRIDG model (HL7 compatible)
  - Goal is interoperability and increased connectivity to allow electronic data exchange
- Working with support from NCI (caBIG) and Univ Minnesota (BCIB) to develop a physical model which can be adopted by centers for their HCT data
BRIDG 3.2
Current version

• Includes: Hematopoietic Cell Transplant (HCT) Database

• This project is designed to produce a BRIDG-compatible model and database (with associated Common Data Elements (CDEs)) covering the scope of federally-mandated data submission from all transplant centers to the Stem Cell Transplant Outcomes Database (SCTOD).
  • Informational BRIDG model (between conceptual and logical models)

• Available at: http://bridgmodel.nci.nih.gov/download_model/bridg-releases/release-3-2
Joint Modeling Exercise between MD Anderson, NCI, CIBMTR, NMDP

Adding the concept of ‘Donor’ to BRIDG

BRIDG → HL7 Regulated Clinical Research Information Management (RCRIM)