Disclosures

I have no conflicts of interest to disclose.
Objectives

• Review the current state of CIBMTR applications
• Update on recent accomplishments and future plans
• Review current approaches to improve end user experience
Agenda

• CIT Objectives and current state of applications
• Review 2013’s focus on user satisfaction
  – Tandem Feedback
  – Site visit discovery at 22 centers
  – Performance release in August 2013
  – User Perspective feedback
    • FormsNet3 Surveys in August 2013 and February 2014

• Forms Revision release in October 2013
• AGNIS updates

• 2014 Enhancements
• Exercise/ feedback opportunity
Purpose of CIBMTR IT

• Facilitate…
  – CIBMTR Mission
  – Data to Knowledge Continuum
  – Strategy
  – Analysis
  – Collaboration

• Create & maintain leading edge technology solutions
  – Increase ease of data entry, usability and user experience
  – Promote data quality throughout the life cycle
  – Provide your data back to you in ways you find value
Purpose of CIBMTR IT (cont.)

• Implement effective and efficient processes that ensure high-confidence execution
  – Portfolio, Program, Project Management
  – Quality Assurance
  – Performance
  – Productivity

• Deliver robust, high quality data
  – Ensure seamless flow of high quality data from source to all stakeholders
  – Provide reports with value to manage the application and our data stream & quality
  – Increase meaningful use of the data by the transplant community
Facilitating Data to Knowledge Hierarchy

- Data
  - Collecting
  - Organizing
- Information
  - Summarizing
  - Validating
- Knowledge
  - Analyzing
  - Interpreting
  - Decision-making

- Experience
- Wisdom
- Patterns
- Calculations
- Relationships
- Standardization
- Facts
- Observations
CIT Data Collection Solutions

FormsNet
Recipient
Donor
Clinical Trials
Sample Tracking
Auditing/ Monitoring
AGNIS

Metadata Analysis: Data about data discipline that is threaded throughout the solutions
FormsNet Timeline

• FormsNet2
  – December 2007 – FormsNet2 Recipient
  – August 2009 – Donor migrated from FormsNet1 to FormsNet2
  – January 2010 – Clinical Trials Module added to FormsNet2 (CIT team created!)

• FormsNet3
  – 2011 - FN3 requirements and stakeholder input
  – December 2012 – FormsNet3 Recipient
  – March 2014 – FormsNet3 Donor
  – 2014/2015 – FormsNet3 Clinical Trials
The Future of FormsNet

• Build upon the successes
• Learn from feedback opportunities
• More involvement with users
• Continued performance improvements
2013 Tandem Feedback
Summary of feedback

Greatest areas for improvement:

- Logout issues (fixed week before Tandem)
- FireFox issues (fixed the week after Tandem)
- Printing from public site and application (fixed in August)
- Application performance (enhanced in August)
- Understanding validations and smart navigations
  - Improved with new revisions

Average rank was 6.4 (out of 10)
CIBMTR Site Visit Summary
Site Visit Purpose

• Understand each center’s technology needs
• Listen to your ideas on how to enhance communication, training, applications, and any aspect of data management
• Improve our relationship with you, to better understand how to meet your needs
• Demonstrate that we are responsive to your needs
Site Visit Agenda

Discovery sessions with center staff:

– FormsNet issues/feedback
– Electronic data transmission options
– Data management Services
  • Data collection
  • Communication
  • Training
  • Best practices
Where We Went

University of Arkansas for Medical Sciences, Little Rock AR
University of California San Francisco Medical Center, San Francisco CA
Stanford Hospital & Clinics, Stanford CA
City of Hope National Medical Center, Duarte CA
USC/Kenneth Norris Cancer Hospital, Los Angeles CA
All Children's Hospital, St Petersburg FL
H. Lee Moffitt Cancer Center and Research Institute, Tampa FL
Children's Healthcare of Atlanta at Egleston, Atlanta GA
Emory University Hospital, Atlanta GA*
Dana Farber Cancer Institute - Peds and Adults, Boston MA*
Massachusetts General Hospital, Boston MA
Duke University Medical Center, Durham NC
Duke University Medical Center; Pediatric BMT, Durham NC
Hackensack University Medical Center, Hackensack NJ*
Cincinnati Children's Hospital Medical Center, Cincinnati OH
University Hospitals Case Medical Center, Cleveland OH
Cleveland Clinic Foundation, Cleveland OH
Oregon Health and Science University, Portland OR
Vanderbilt University Medical Center, Nashville TN
VA Tennessee Valley HCS HSCT Program Nashville, TN
Fletcher Allen Health Care - University of Vermont, Burlington VT
Fred Hutchinson Cancer Research Center, Seattle WA (2 days)
Additional Insights

• Form entry is much more than data entry
• Every center is different
  – Culture
  – Data collection approach
  – Staffing
  – Interaction with the transplant center
• Centers want to participate in prioritization and testing
• Positive feedback on CRC liaisons
  – Your 1st contact for questions and problems
Site Visit Insights
244 action items recorded

Follow-up letter sent to centers responding to each action item.

Categories:
- AGNIS (43)
- FN3 (43)
  - Enhancements (15), how to, browser, defects (4), hot keys, performance (8), UI, printing (12)
- Communication (29)
- Training (21)
- Forms Revision (18)
- Validations (8)
- General (82)
Summer Performance Release

Center participation helped to determine the scope of the Summer Performance Release
Here are the immediate results that were delivered:

- Improved performance across the application and enhanced printing functions.
  - Reduced the number of pages by approximately 50%
  - "Else go to" instructions were removed
  - Vertical lists of question options were changed to horizontal in the paper forms.
  - The 15 most commonly used blank Recipient forms were reformatted and on our website.
Summer performance release (continued)

• Three transplant centers participated in User Acceptance Testing to ensure that the performance release met user needs.

• They discovered conditions unique to the user environment that were able to be resolved prior to release.
August Survey Results

- Mirrored the Tandem and site visit feedback priorities to address printing capabilities, enhance form workflow and improve application performance.

- Two key updates were implemented:
  - August 2013: The Summer Performance Release
  - October 2013: The Forms Revision Release

- Worked with our internet service providers to establish monitoring and triage techniques to more quickly assess problems in performance that impact the FormsNet application.
February 2014 survey results

- Survey of principal data managers
- Asked to rank overall satisfaction from 1-10
- 75.2% rated the application from 6-10 for satisfaction
- 24.8% rated the application from 1-5 for satisfaction
- Overall rank of 6.7
February survey results (cont.)

- We asked for satisfaction on the new functionality in FormsNet3 that allows you to print a form in any status. We have made style changes that streamlined the forms and reduced the number of pages by more than 50%.
- 81% rated exceeds or meets expectations

<table>
<thead>
<tr>
<th>Description</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exceeds expectation</td>
<td>29%</td>
</tr>
<tr>
<td>Meets expectation</td>
<td>52%</td>
</tr>
<tr>
<td>Does not meet expectation</td>
<td>19%</td>
</tr>
</tbody>
</table>
February survey results (cont.)

- We released a new version of the blank forms on CIBMTR.org. How frequently do you access the blank forms?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>8.90%</td>
</tr>
<tr>
<td>Weekly</td>
<td>22.30%</td>
</tr>
<tr>
<td>Monthly</td>
<td>29.50%</td>
</tr>
<tr>
<td>Never</td>
<td>39%</td>
</tr>
</tbody>
</table>
Additional assistance available

• When centers have experienced performance issues, we have employed web-exs involving members of our tech team, center representative, and a CIBMTR CRC.

• Success has been achieved in resolving issues

• See your CRC if you have an issue you would like addressed in this manner.
Forms Revision Release
The upgrade of 26 Recipient forms in FormsNet3 was completed on October 29, 2013.

Purpose of the upgrade:

- Align the data collection forms with current treatment practices
- Provide significant new functionality that enables enhanced user experience with cleaner validations and additional auto-population
- Support the collection of relevant data that aligns with our scientific mission, and improve the quality of data submitted by modifying question text and validations
## Forms Revised in October 2013

<table>
<thead>
<tr>
<th>TED/CRF Forms</th>
<th>Disease Specific Forms</th>
</tr>
</thead>
<tbody>
<tr>
<td>2804 - CIBMTR Recipient ID Assignment</td>
<td>2010/2110 - Acute Myelogenous Leukemia</td>
</tr>
<tr>
<td>2400 - Pre-TED</td>
<td>2011/2111 - Acute Lymphoblastic Leukemia</td>
</tr>
<tr>
<td>2000 - Recipient Baseline Data</td>
<td>2014/2114 - Myelodysplasia / Myeloproliferative Neoplasms</td>
</tr>
<tr>
<td>2004 - Infectious Disease Markers</td>
<td>2015/2115 - Juvenile Myelomonocytic Leukemia</td>
</tr>
<tr>
<td>2005 - Confirmation of HLA Typing</td>
<td>2016/2116 - Plasma Cell Disorders (Forms 2017/2117 AMY and 2016/2116 PCD have been combined)</td>
</tr>
<tr>
<td></td>
<td>2019/2119 - Waldenstrom's Macroglobulinemia</td>
</tr>
<tr>
<td></td>
<td>2034/2134 - X-Linked Lymphoproliferative Syndrome</td>
</tr>
<tr>
<td></td>
<td>2039/2139 - Hemophagocytic Lymphohistiocytosis</td>
</tr>
<tr>
<td></td>
<td>2056/2156 - Pigmentary Dilution Disorders (New Forms)</td>
</tr>
</tbody>
</table>
Forms Revision Release Activities

- The Data Management Instruction manuals were also updated

- Learning modules were provided on the Learning Management System (LMS)

- All blank forms for printing are available on the Data Collections Forms page of the CIBMTR website
AGNIS (A Growable Network Information System) Overview

- AGNIS is a method to submit, edit and retrieve forms electronically.
- It enables centers to avoid entering data more than once.
- Same form (data) may be accessed via FormsNet or AGNIS
AGNIS Operations

• Submit form
  – Data is entered into FormsNet
    • All FormsNet validation rules apply
  – Current form content is returned

• Retrieve form
  – Data is returned from FormsNet
    • Includes data entered through the FN user interface
  – Can retrieve single form or all complete forms
  – Acknowledge form retrieval to receive only new forms
  – Driven by AGNIS’ PUBLISH service (CIT function only)
AGNIS – 2013 Accomplishments

- AGNIS facilitates communications between FormsNet and other databases
- Data elements for CIBMTR forms are in NCI caDSR library
- EBMT-CIBMTR and CIBMTR-Eurocord AGNIS connections in progress – EBMT has submitted >8,000 initial forms and is beginning to send follow-up forms for those transplants (for 50 centers)
- Other users submitting data through AGNIS:
  - 4 centers making direct submissions
  - 1 registry supporting 50 centers
  - 6 vendors certified for production submission
- Other users retrieving data from FormsNet through AGNIS:
  - 2 centers doing direct retrieval
  - 4 vendors supporting center retrieval
2014 Enhancements

• Updates to FormsNet3 Recipient
• Study support for RCI-BMT and clinical trials
• Additional Auditing functionality
• Implementation of FormsNet3 Donor module
IT Communication forums today

• Training / communication team
  - Monthly newsletters & eblast emails
    • Items related to FormsNet releases occasionally included

• Your CRC liaison

• Landing page/login page within FormsNet 3

• Fnquestions@nmdp.org email
Feedback opportunity on communication

• Take 10 minutes to reach agreement
  – What one thing could be done to improve communication.
  – Focus areas: Scope of releases, notification regarding release dates, known defects

• Each table:
  – Present top 2
  – All ideas will be collected
Questions?