What is the MAIN goal ?!

- Provide an equitable, balanced, scientific performance measurement tool(s) that can be used by the profession to define and improve quality. While:
  - Acknowledging limitations
  - Avoiding misuse/misinterpretation
  - Striving for continuous improvement
- Be a resource to support the HCT community
How do we maintain engagement of the HCT community?

What is the center outcomes forum?

- Bi-annual meeting to discuss the center specific survival analysis for hematopoietic cell transplantation (HCT) – the highest impact report produced for the Stem Cell Therapeutics Outcomes Database (SCTOD)
- Invitees include:
  - HCT centers/community, ASBMT Quality Outcomes Committee, biostatisticians, quality and reporting methodologists, patients, payers, National Institutes of Health/Office of Naval Research/Health Resources and Services Administration representatives
- Held in MKE, MSP with average costs < $50,000
- Highly rated by attendees
What is the purpose?

• Engage the relevant stakeholders in meaningful discourse about the process and with each other regarding uses and expectations
• Transparency and accountability
• Acquire meaningful input on statistical methodology, risk adjustment methodology, relevant data collection, meaningful display of results, appropriate use and avoiding misuse, adaptation to future trends in quality reporting.

What is changing in the national quality reporting landscape?
Our Challenge – How do we adapt?

• Do we face a trade-off?
  – Increasing depth of measurement and adjustment surrounding Overall Survival OR
  – Adding additional outcomes to reflect quality for HCT

• How can CIBMTR improve the process and provide greater value while recognizing our domain of influence.

Key Question 1:

• Which sociodemographic/socioeconomic status (SES) factors should be used in center-specific survival analysis beginning in 2016, with group consensus on their value and importance and recognizing balance of benefit and burden of data collection?
KQ1: Which (SES) factors should be used in center-specific survival analysis beginning in 2016?

- Important and Feasible Recipient factors
  - Insurance Status
  - Zip code of residence
  - Race/ethnicity
  - Level of education
  - Marital status
- Action plan: Add the additional data elements to the pre-TED in required data cycle.

Key Question 2:

- What reports can CIBMTR produce using existing data that will facilitate centers’ quality improvement efforts?

- Recommendations
CIBMTR Action on Reports for Centers

- Expand existing descriptive reports
  - More data/variables: expanded HCT-CI and KPS, graft source, manipulation, gvhd prophylaxis, clinical trial participation
  - Better views: Add pediatric only, high performing centers “comparison” columns to the existing columns for individual center and all US centers
- Additional descriptive outcomes
  - Descriptive outcomes for acute and chronic GVHD in addition to 100d, 6mos, 1 year OS
- Better access to individual center dataset

CIBMTR Action on Reports for Centers

- Carefully consider whether descriptive benchmark reports can be useful
  - Cohort of HCT recipients that has clearly defined disease and other risk factors with...
  - Sufficient numbers of patients at centers
  - To provide meaningful QI information
- Better access to individual center datasets
- Discussion with ASBMT Quality Outcome Committee/FACT re other ways of analyzing data for centers to identify improvement opportunities
Benefits and Risks of additional reports for centers

• Substantial value for centers
  – Individual center ad hoc data requests for QI efforts increasing substantially last 3 years

• Providing scheduled data rather than by request

• Connects centers to their data – and its quality

• **Risk:** Data is really meant for local center consumption and action

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Key Question 3:

• **What are the characteristics of transplant centers with consistently high outcomes that may be adoptable by other transplant centers to improve or ensure transplant results?**

• **After reviewing the CIBMTR Center Characteristics Survey, on a scale of 1-5 (where 5 is greatest value), how valuable would it be for CIBMTR to perform an analysis to associate these center-based factors with outcomes performance?**
Key Question 3?

- Strong consensus that collection of center characteristics and analysis to associate with outcomes was valuable.
  - Continue to collect the organizational and care delivery characteristics periodically
  - Guidance for additional survey questions provided
  - Resourcing allocation and staffing models at centers to accomplish work
  - Studies to understand best practices through the HSR committee

KQ3: CIBMTR Actions

- Collaborate with FACT regarding audit performance and center education about QI process, procedures, best practices
- Excellent ideas provided for next center characteristics survey
- Opportunity to collaborate with UHC, FACT on development and collection of center specific characteristics through periodic surveys
Key Question 4:

• Are there new measures of quality not currently reported publicly by the CIBMTR which should be included in future iterations of the center-specific survival analysis (with risk adjustment) on behalf of the HCT community?

KQ4: New quality measures?

• Develop and test a 3 year risk adjusted overall survival measure – pilot for center use
  – Anticipate pilot testing this in the coming year’s report (HCT 2009-2013)

• Assess feasibility of collecting and reporting Patient Reported Outcomes
  – QOL pilot analysis in progress to inform future work
  – Exploring tools by which CIBMTR and centers can collect these data
    • EMR or PROMIS (NIH)
KQ5: Which cellular infusion types should be considered in the CIBMTR center-specific survival analysis?

- Continue to broadly collect information regarding indications and utilization of cellular therapies to maintain surveillance of the field and conduct research.
- Use traditional HCT as the focus of the center-specific survival analysis for reporting on center performance for quality improvement efforts in the United States.

What about cost/ value?

- CIBMTR recognizes opportunity to connect detailed clinical data with claims-based data on behalf of centers and HCT community
- Initial meetings with UHC April 2015 confirmed mutual desire to explore combining data
- Follow-up to address:
  - Individual data agreements between centers and CIBMTR and UHC
  - Data sharing process, procedures and agreements between UHC and CIBMTR
Improving the public facing display

Publicly Available Data Task Force Recommendations Update
Executive Summary

General principles for presenting information on websites suggested by the Task Force include

- Following a logical “flow” of interest to the patient
- Providing the same data and time frames across websites (BTM and .gov)
- Improving accessibility, navigation, and language to increase ease of use and highlight information for patients

Executive Summary Continued

- Focus efforts on improving the information already displayed on its public websites as delivering the greatest return on investment.
- Improve the visibility and accessibility of information available as static information and in queries to increase value for the public user of the CIBMTR websites.
- Re-design the query tools supporting the public website to increase flexibility and user-customization options to provide more information for users.
- Ensure that query tools do not compromise the privacy of those patients whose data are contained in the database.
- Make complex information & specific data sets available to centers and scientists via established CIBMTR processes
Plans and Progress to Address Recommendations

- Improve information already displayed
  - Full redesign of TC Directory
  - Add longer term survival data
  - Provide other outcomes data
  - Remove regimen intensity from table
  - Ensure data consistency across sites

- Improve accessibility, navigation and language
  - TC Directory Redesign
  - Center Specific Outcomes graphical display
  - Disease groupings & descriptions / Disease Glossary

- Improve query tools
  - Map-based query in TC Directory
  - Enhanced .gov query
    - Disease selection
    - TC
    - Multiple criteria
    - Query layers

- Improve visibility and access to data as static information
  - Display Annual Statistical Reports on .gov site

What are the limitations?
Limitations

• Only outcome is 1 year survival (for now)
  – Only one outcome, only one year
  – Balances HCT center control, type of regimen, preferred long term outcome desired by patient/society
• Is not sufficiently ‘real-time’
• Report issued annually - Jan 2015
• Does not sufficiently adjust for risk factors associated with income/ SES
  – Balance challenges and benefits of data collection

Limitations

• Does not address ‘value’ (beyond outcome)
  – No cost data – increasingly of interest to payers, patients, policy makers
  – Costs among most rapidly growing (AHRO Report 2010)
  – About $500,000 billed first 180 days after alloHCT (Friedman, Optum 2012)
  – Cost variation ??? related to risk
• Cannot be used to predict future performance
• Translating results into performance improvement is challenging
Limitations

• Autologous HCT are NOT included
  – Full representation/reporting essential
• Conveying data to the non-statistician
  – Misunderstandings & misrepresentation
• Unintended consequences
  – Not intended to directly compare centers
  – May inappropriate affect patient selection for HCT
  – May stifle investigational approaches

Learn more at:

• http://www.cibmtr.org/Meetings/Materials/CSOAForum/Pages/index.aspx