Center Outcomes Reporting in HCT: Progress on Recommendations from the Center Outcome Forum 2014

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A research collaboration between the National Marrow Donor Program (NMDP)/Be The Match and the Medical College of Wisconsin

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

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How do we maintain engagement of the HCT community?

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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)
- 1-2 day meeting 2008, 2010, 2012, 2014
- 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

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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.

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What is changing in the national quality reporting landscape ?

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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.

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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?**

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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.

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Key Question 2:

- **What reports can CIBMTR produce <u>using existing data</u> that will facilitate centers' quality improvement efforts?**
- **Recommendations**

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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

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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

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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?**

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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

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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

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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?**

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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)

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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.

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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

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Improving the public facing display

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Publicly Available Data Task Force

Recommendations Update

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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

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*Transplants for AML, MDS, and AML in 2012

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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

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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

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What are the limitations?

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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'
  - 2014 report, includes HCT 2010 – 2012
- Report issued annually - Jan 2015
- Does not sufficiently adjust for risk factors associated with income/ SES
  - Balance challenges and benefits of data collection

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Limitations

- Does not address 'value' (beyond outcome)
  - No cost data – increasingly of interest to payers, patients, policy makers
  - Costs among most rapidly growing (AHRQ 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

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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 inappropriately affect patient selection for HCT
  - May stifle investigational approaches

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Learn more at:

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

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