

## **Summary and Recommendations of the 2010 Center Outcomes Forum Held on September 10, 2010**

### **Background**

In 1986, the National Bone Marrow Donor Registry (managed by the National Marrow Donor Program (NMDP)) was established, with responsibility for the maintenance of an unrelated donor registry for hematopoietic cell transplantation (HCT). In 1990, the Transplants Amendment Act made the reporting of center-specific outcomes for unrelated donor HCT mandatory in the United States. This activity has been conducted by the NMDP since 1994. With the Stem Cell Therapeutic and Research Act of 2005, the requirement to report outcomes of HCT by transplant center was broadened to include all allogeneic (related and unrelated) HCTs in the United States. This responsibility rests with the contractor for the Stem Cell Therapeutic Outcomes Database, the Center for International Blood and Marrow Transplant Research (CIBMTR).

The CIBMTR has collaborated closely with the NMDP since 2003 in the generation of center outcomes reports for unrelated donor HCT for the Health Resources and Services Administration (HRSA), a division of the U.S. Department of Health and Human Services. These reports are well-accepted by the HCT community. However, the Stem Cell Act of 2005 substantially expanded the patient population to be considered in these analyses. At most centers, the new requirement means that the percentage of patients included at least doubled. Centers that do not perform unrelated donor HCTs were included in these analyses for the first time.

During the transition phase of the C.W. Bill Young Cell Transplantation Program, CIBMTR, working with the NMDP, the American Society for Blood and Marrow Transplantation (ASBMT) and HRSA, held a meeting to review the current approach to center-specific outcomes reporting and to provide recommendations for future reports in the expanded Program. With this purpose, CIBMTR invited representatives of the HCT community (national and international), the ASBMT Quality Outcomes Committee, governmental funding agencies, the solid organ transplant community, patients, private payers, statisticians and experts in hospital and quality outcomes reporting to Milwaukee, Wisconsin in September of 2008.

The objectives of the meeting were to review the current state of center-specific outcomes reporting in medicine and transplantation and to openly discuss strengths and limitations of current approaches with the goal of developing recommendations for HCT center outcomes reports that would be:

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- scientifically valid;
- equitable;
- free from bias;
- useful to the HCT community for improving quality;
- informative for the public.

One of the recommendations of the 2008 meeting was to hold regular reviews of the process. The second Center-Specific Outcomes Analysis Forum was held on September 10, 2010. Presentations covered topics regarding current center outcomes methodology in HCT, risk factors known to affect HCT outcomes, risk adjustment in outcomes reporting, best outcomes to analyze, outcomes for investigational HCT and presentation of outcomes to the lay community. What follows is a summary of the discussion and recommendations from this meeting, organized by general topic.

Until 2009, the published outcomes report has included a risk-adjusted analysis of one-year survival for unrelated donor transplants in the United States, and:

- Included all transplant centers;
- Included all transplant recipients over a five-year interval;
- Adjusted for multiple known risk factors;
- Presented 95% confidence interval for predicted survivals at each center.

The report produced in 2010 will include both related and unrelated donor transplants in the United States, as well as several new data elements (comorbidity, cytogenetics in AML, distance from transplant center, and a surrogate measure of patient income).

Based on the experience of preparing this report in 2010 and in response to feedback from centers, several changes will be made in 2011. The CIBMTR will:

- Improve communication with HCT centers with greater frequency and inclusion of the center director on all related correspondence.
- Integrate center outcomes reporting process better with overlapping Program components, including center volume reports, Continuous Process Improvement (CPI) trimester requirements, and proactive communication regarding forms-based errors.
- Review data completeness early in the data preparation phase, and notify centers with insufficient follow-up as quickly as possible.

## **CONSIDERATIONS FOR STATISTICAL ANALYSIS OF CENTER EFFECTS**

### ***Case Mix Score***

A “case mix score” is calculated to describe the sickness/severity level of patients transplanted at a center. It is calculated by computing the predicted survival for each patient and averaging across all patients at a center. The scores are presented as quintiles of centers’ predicted outcomes. Centers whose patients have the highest predicted survival, on average, are assigned a case mix score of 1. The potential uses of a case mix score are to determine which centers have the best performance with patients with the

most severe illness; whether some centers may be performing transplants that are considered more risky, and to place an individual centers' results in context with others of similar overall case mix.

However, in reviewing the characteristics of the case mix score in the 2010 report, there is little spread between the middle three quintiles, which limits the utility of presenting these data. Discussion at the forum focused on whether the information could be presented so patients would understand how a particular center compared with an average center and whether results can be presented to centers based upon case mix such that performance can be compared for “high risk” and “standard risk” patients. There was consensus that case mix score was difficult to comprehend and less useful for presentation to patient groups. But, understanding performance by center stratified by “risk score” may provide valuable information for centers to determine whether their individual performance is driven by outcomes in the standard or high risk patients. Additionally, centers that perform better than expected with high risk patients may be a source for valuable practice improvement suggestions to other centers. Internally, CIBMTR can develop the risk adjustment models in an iterative approach by analyzing the models with and without high risk patients to determine their contribution to the overall outcomes.

Suggestions for improvement included presentation of survival curves to individual centers, including a summary of their “case mix score”, and providing centers with survival information stratified by risk with comparison to national aggregate data. Presentation of the “case mix score” may be useful in reports for payers in the future, and should be a topic for consideration at a future center outcomes forum. Risk scoring and its usefulness for patients should be considered by patient focus groups convened by OPA/SPA, particularly how the information, if presented, can be made readily understood.

#### Recommendations:

- Do not use “case mix” for the public presentation of results.
- Provide information to centers regarding their case mix, and survival stratified by risk with comparative national data as a potential performance measurement tool. (See section “*Making additional data available for center’s performance improvement efforts*”.)

#### ***Combined related and unrelated HCT in statistical model***

Center outcomes reports have included only unrelated donor HCT until 2010. One recommendation from the 2008 Forum was to include both unrelated and related donor HCT data in a combined model once related donor outcome data became available. Related and unrelated HCT can be analyzed in either a separate or a combined model. Benefits of a combined model include more stable estimation because of a larger sample size and the ability to use a shorter time window for analysis in future years. Weaknesses include a requirement for adequate follow-up for both related and unrelated HCT at participating centers for inclusion, and the possibility of not distinguishing unique factors that may affect outcome for either transplant type individually, such as donor selection

algorithms unique to unrelated HCT or other specialized approaches. That is, factors affecting survival may be different between related and unrelated HCT and these differences may not be adequately captured by the current risk adjustment models. Likewise, centers performance may be substantially different for related and unrelated HCT; although modeling would capture this, it would not distinguish between the two for a given center's results, even though marked differences in outcomes between related and unrelated donor HCT within a single center are unexpected.

CIBMTR tested the assumption that related and unrelated HCT could be modeled together for the 2010 report. The results suggest that factors affecting survival are similar between the two groups. When reviewing results by center, of 157 centers included in the report, the performance against expected was only affected at 6 centers when considering combined versus separate modeling for related and unrelated HCT. However, the 2010 analysis only included related HCT from one year (2008), compared to 5 years of unrelated HCT. Therefore, the related HCT may be relatively under-represented, and re-evaluation of combined modeling was recommended for the 2011 report.

It was noted that the covariate for related versus unrelated HCT is irrelevant if a center only performs related HCT. Cord blood HCT were generally unrelated HCT and double cord blood HCT were included in the model.

Recommendations:

- Continue to model outcomes based on a combined model of unrelated and related HCT.
- Re-evaluate model performance of combined versus separate models in 2011 when additional related HCT data are available to increase sample size. Present survival data for related and unrelated HCT in reports to individual transplant centers.

***Criteria for inclusion of HCT centers***

It is expected that whenever possible, all U.S. HCT centers performing allogeneic HCT will be included in the center outcomes report. However, completeness of reporting and follow-up is critical to appropriate outcomes analysis. Required completeness of reporting follow-up at one year for a center to be included in the 2010 report was 75% reporting overall and 50% reporting for related donor HCT. This expectation for related donor HCT follow up was set lower than previous year's reports as this was the first year of inclusion of related HCT. However, concern was expressed that centers may neglect to report follow-up on patients doing poorly with the expectation set this low. Biased reporting would substantially affect center's reported performance. There was strong consensus that follow-up expectations for centers be increased sequentially in the next two years to reach at least 90% of expected follow-up for inclusion in the analysis. Further consideration should be given to a final expectation of 95% completeness of follow-up.

Understanding concerns about completeness of reporting and the potential for bias, use of the National Death Index (NDI) was recommended as a way to verify completeness of

survival reporting. This strategy may not be effective for any given year, as there may be a lag of as much as two years for a death to be reported and patient-matching may be difficult since Social Security Numbers are not required by CIBMTR. However, the NDI tool may provide a secondary check on quality of reporting for centers. Since this was the first year of reporting related HCT, CIBMTR anticipates that the completeness of follow-up for centers will improve next year.

Implementation of the CPI program and continuing the center volumes reporting process are also likely to serve as reminders to centers to maintain consistent reporting.

Recommendations:

- Require completeness of follow-up for related and unrelated HCT forms of 85% in 2011 and 90% in 2012 as inclusion criteria for center outcomes analysis.
- Provide a letter from CIBMTR for Medical Directors outlining the expectations of the Program for center outcomes reporting which can be used by centers to advocate for increased staffing to meet these requirements.
- Consider allowing submission of the Death Form (Form 2900) following HCT for those recipients who are deceased to represent sufficient follow-up for inclusion in the Center Outcomes Report, as long as pre-HCT reporting forms are complete.

***Methods of model building and determination of significant risk adjustment factors***

Model building to adjust for patient, disease and transplant characteristics for the center outcomes analysis has traditionally used a p-value of 0.05 as the significance level for inclusion of a factor in the final adjustment model. However, large datasets may allow some variables to be statistically significant based on sample size rather than true magnitude or meaningfulness of effect. Similarly, being too permissive with the significance level of interactions between covariates may create convoluted results. Conversely, a strict p-value of 0.05 may eliminate from consideration in the final model a factor that is universally considered to have clinical significance (e.g. prior autologous HCT) in affecting survival.

An alternative approach that would account for these issues is to build the risk adjustment model by considering all variables with p-values less than 0.10 *and* the size of the Odds Ratio (OR) for the variable. This would introduce clinical judgment for importance of covariates for the final model. Similarly, candidate interactions to be tested in the models would be reviewed *a priori* (e.g. HLA matching/graft type/donor type) and directed testing for significance of those interactions would occur at a p-level of significance of 0.01. Because clinical judgment would be required, an external reference such as the ASBMT Quality Outcomes Committee could be asked to participate in this process. Finally, directed interaction testing may introduce different interactions between adult and pediatric HCT recipients.

Although there is broad interest in collecting sufficient information for risk adjustment, it was also acknowledged that limitations exist as to the ability to collect information on all potential variables that may affect “risk” for adjustment in modeling systems. Data to be considered for risk adjustment should have sufficient supporting evidence in the medical

literature, should be readily available at all or most HCT centers, should be objective and reproducible across centers, and should be reasonably interpretable to data professionals who submit the data. Several suggestions for general risk factors to collect included zip code of residence, income of recipient, TERS (Transplant evaluation risk score), and insurance status. Zip code of residence was identified for ongoing data collection as generally available and easy to provide. Although there was interest in the TERS, it was acknowledged that it does not meet the general criteria for inclusion given its dependence upon a psychosocial evaluation for each recipient. Additional disease-based risk factors were discussed, including cytogenetics in AML. These data are not available on all CIBMTR data collection instruments at this time, but will be considered for future forms revisions.

#### Recommendations:

- Change the p-value of significance for retention of variables in the final risk adjustment model to 0.10 with consideration of the OR for magnitude of effect.
- Identify candidate interactions clinically *a priori* and test for significance using a p-value of 0.01.
- Incorporate the ASBMT Quality Outcomes Committee and CIBMTR Scientific Directors into the process to identify candidate interactions for interaction testing.
- Continue to identify and consider new elements relevant for inclusion in model-building based upon process outlined at 2008 Center Outcomes Forum, as well as input from the ASBMT Quality Outcome Committee and future Center Outcomes Forum meetings.

## **REVIEW OF OUTCOME MEASURES AND SAMPLE SIZE CONSTRAINTS**

### ***Time window for inclusion in analysis***

The current center outcomes report uses all transplants within a *five-year time window*, in order to increase the power of the analysis. The five-year time window may be particularly advantageous when considering rare indications for transplantation, factors that have a small magnitude of effect, or centers that are small, including pediatric centers. Criticisms of this approach include concern that the wide time range does not adequately reflect programmatic changes that may occur during the interval and does not sufficiently focus on most recent results. A five-year window provides greater power to identify significant covariates and interactions, but can perpetuate the negative impact from one bad year on a center for a longer period of time. Historically, centers falling below the confidence interval for expected survival knew there was an issue, showed concern, and made improvements. However, these improvements may not be well reflected in the reported survival when a five-year window is used.

With the inclusion of related HCT in the risk-adjustment model, annual sample size for transplant centers increases, and may allow adequate modeling using fewer years of data. This was an important recommendation of the Center Outcomes Forum in 2008. The benefit of using a three-year time window is that most recent outcomes, which are of the most interest to stakeholders, are reported. Potential weaknesses include less stable

models due to smaller numbers for analysis and the reliance on combined related and unrelated HCT in a single risk adjustment model. Analysis of the combined related and unrelated HCT model for the 2010 center outcomes analysis, where only one year of related HCT outcomes could be included, suggests that factors affecting related and unrelated HCT outcomes are similar and that model performance using a three-year time window may be sufficient. (See also “*Combined related and unrelated HCT in statistical model*”.)

It was proposed to select variables for inclusion in the multivariate adjustment models based on three years of data if feasible or five years if unstable, then use a three-year time window for the final multivariate risk adjustment model and report observed and expected survival based on three years of outcomes for centers.

#### Recommendations:

- Evaluate appropriateness of a three-year time window for analysis in 2011 with goal of reporting center outcomes based on a three-year time window.
- If necessary, identify candidate variables for risk adjustment using five years of outcome data, and introduce these candidate variables into a three-year time window for final multivariate adjustment.
- Report center outcomes based on three-year rolling time window.
- Make centers aware in advance of this important change.

#### ***Outcomes to measure***

The current report presents one-year survival, based on a recommendation from the 2008 Forum. It was agreed that although 100-day survival provides a useful measure for centers to assess early results that are most directly influenced by their practices, it is not the best measure of a center’s overall performance. There are several limitations to the use of 100-day survival. Although reduced-intensity preparative regimen approaches reduce the mortality in the early post-transplant time period, some complications and mortality is shifted into the time period beyond 100 days. This differs from fully ablative regimens, and a measure at 100 days would not facilitate equal comparisons between these approaches. Additionally, use of an early mortality outcome could serve to discourage centers from performing HCT in higher risk patients, and may encourage use of inappropriate practices to extend survival beyond 100 days in patients with life-threatening illness who otherwise might not undertake treatment (e.g. refractory GVHD, refractory relapse). Finally, patients are most interested in long-term survival as their goal after HCT.

Consideration was given to adoption of survival at two years as the reference measure. This presents the advantage of aligning better with patient (and provider) long-term goals from the HCT, and certainly reflects a long enough period to account for differences in preparative regimen approach. Survival at two years also reflects better outcomes from longer-term complications of HCT, including chronic GVHD. Long term follow-up practices of centers would be reflected to some extent. However, by two years after HCT most patients have returned to care in their local community, which is less influenced by centers’ practices. Additionally, there is low consensus regarding appropriate late

management of transplant survivors. The difficulties of acquisition of data and reporting longer term outcomes were discussed, and if a two-year survival outcome were adopted, there would be increased censoring for unreported patients and the time window for the analysis would need to increase to accommodate for adequate follow-up reporting (See section “*Time window for inclusion in analysis*”).

Alternative measures were briefly discussed. Long term disease-free survival is an optimal goal after HCT, but there are substantial hurdles to its consistent measurement, reporting, and adjustment in analytic models. Chronic GVHD is an important outcome that centers should be interested in measuring, but is again limited by diagnostic vigilance and location of care delivery (transplant center or local practice).

One-year survival was agreed upon as the outcome with the least inter-center variability in diligence of reporting and the most parsimony accounting for center’s practices and relevance.

Several research topics were generated by these discussions that may bring evidence for future consideration. They include: comparison of outcomes between centers with and without organized long-term follow-up management programs, studies to determine whether late survival differs among patients alive at one year after HCT and factors that predict differences in late survival, investigational analyses to determine whether center effects exist at longer-term time points beyond two years, and correlations between overall survival and disease free survival at one, two and three years after HCT.

Since an overall goal of the Center Outcomes reporting process is to provide tools for centers to measure and improve performance, several of the outcomes discussed above represent candidate measures to provide to centers on an annual basis as univariate analyses.

#### Recommendations:

- Retain one-year survival as the outcome measure for the center specific outcomes analysis and public reporting.
- Continue to develop and perform research studies that explain late mortality and explore factors associated with long term survival.
- Use data collected by CIBMTR to augment center specific survival reports with other outcomes data useful for centers’ individual quality improvement efforts, including normative U.S. data. (See also “*Making additional data available for center’s performance improvement efforts*”)

#### ***Handling small centers***

A common question is whether outcomes at small centers should be handled differently than larger centers when considering observed versus expected outcomes, since their sample size leads to wide confidence intervals surrounding expected one-year survival. In other words, at a small center a substantial number of deaths would need to occur before the mortality would be considered statistically significantly different from expected. The



consensus at 2008 Forum was to treat small and large centers similarly, as confidence limits “protect” small centers.

There was general consensus to continue to handle small centers in similar fashion to large centers, acknowledging that small centers will have wider confidence limits surrounding their expected performance. The perception that small centers have a greater likelihood to fall outside confidence limits for expected outcomes was not apparent in the 2010 analysis. This center size effect can be formally tested. However, center volume is not considered an appropriate covariate for inclusion in the multivariate model.

Recommendations:

- Continue to handle small and large centers using the same methodology.
- Consider formal testing for a “center size” effect with regard to center outcomes, particularly in the context of future research studies.

**PROCESS FOR INTRODUCTION OF NEW FACTORS IN THE CENTER OUTCOMES REPORT**

*New Elements for the Statistical Analysis*

Consensus at the 2008 Forum was to introduce and test performance of the Sorror Comorbidity Index<sup>1</sup> in the multivariate analysis for one-year survival. The Sorror Index is the best established, yet is subjective and imprecise. There was suspicion that inter-center differences exist in how centers characterize and report the comorbidity score. Manual review of data used in the 2010 report reveals that many centers use the “other specify” field to report conditions that would not normally be considered significant. Nonetheless, 2010 analytic results suggest the performance of the comorbidity index is adequate to discriminate a group of higher-risk patients. The research agenda of the CIBMTR includes studies that seek to validate and refine the comorbidity index, and auditing of centers may reveal important trends in reporting of comorbidity.

Median household income “imputed from zip code” was not predictive of survival in the 2010 analysis. However recipients whose residence was located more than 300 miles from the transplant center had better outcomes. Given these data, it was recommended that the benefits of using the zip code information outweighed the data collection burden, and that zip code should be collected on all HCT recipients.

Recommendations:

- Collect co-morbidities on TED forms as is done currently and re-evaluate over next few years.
- Continue efforts to train centers on what should be reported as a co-morbidity.
- Collect zip code of residence of recipient for all HCT recipients.

*Should pediatric populations be handled differently?*

Pediatric centers present specific challenges, including smaller overall size compared to adult centers, diseases with different risk factors than those in adults, and a wide

distribution of comorbidities and diseases treated. A greater frequency of the diseases transplanted in the pediatric population are non-malignant, and although non-malignant diseases may be considered “low risk” by virtue of the one-year survival, patients with these diseases may have considerable variability in disease severity. Less data is available to recommend approaches to adjust for disease severity at HCT, and there are likely to be strong correlations between some diseases and pediatric centers based on center specialization. Smaller size leads to wider confidence intervals surrounding expected survival estimates. (See also “*Handling small centers*”.)

Data was presented from a small study that suggests the Sorror co-morbidity index may be predictive of non-relapse mortality after HCT in children<sup>2</sup>. However there was considerable variation in reporting of comorbidities across the pediatric centers who participated in the study, and some components of the Sorror co-morbidity score do not apply to children.

There was general consensus to continue to handle pediatric centers in the current fashion, while acknowledging the limitations of the data. CIBMTR should continue to revisit these issues periodically, particularly the comorbidity index, as more evidence becomes available.

Recommendation:

- Continue current methods regarding inclusion of pediatric patients and adjustment for pediatric centers. Methods to deal with outcome estimation at small centers will apply to pediatric centers.

**AVOIDING UNINTENDED CONSEQUENCES OF OUTCOMES REPORTING**

*Accounting for patients on research protocols*

There has been concern that centers doing phase I and II research protocols may be unfairly “penalized” in the outcomes analysis, as results in patients who are enrolled on such protocols are inherently likely to be poor in comparison with standard treatment. Research is important and necessary to make advances in treatment and supportive care that will extend the benefits of HCT, and frequently involves patients with “high risk” situations such as advanced disease. Public outcomes reporting could have the unintended consequence of stifling innovative research if centers reduce their research activity to preserve better outcomes. Current analytic modeling does not specifically capture and adjust for “investigational” research, though individual risk factors of participants are generally included in the models. A system that can identify those patients who would not normally receive a transplant and account for them in a way that would not simply “hide” poor judgment in patient selection would be necessary.

A potential plan for capturing this information was presented and discussed. Factors that could be used to characterize a “high risk research protocol” include a study with distinct IRB approval for research, not considered standard of care (e.g. not supported by several

peer reviewed, reproducible, published studies) that has as its goal at least one of following four features:

- Therapeutic intent of the HCT;
- Use of non-standard cellular products;
- Mitigation of toxicity of high risk therapy;
- Use in high comorbidity or older patients.

There was substantial discussion regarding the proposed criteria and their ability to be implemented. Important characteristics of such a system should include ease of completion and “assignment” of patients, simplicity of recording, ease or reproducibility across centers, and systematically auditable. There was concern that the suggested criteria would not fulfill these requirements.

Other suggestions that arose during the conversations included a more simplistic approach of designating Phase I or II studies whose intent was not supportive care as investigational. Consideration could be given to designating any HCT performed for certain “severe diseases” as investigational, such as those where the expected survival at one- year is less than 30%. Another consideration was to form a neutral panel who would intermittently review research protocols submitted by centers and make determinations regarding status as investigational. Such a review board could also play an important role in the payor coverage process.

A conclusion was not reached during the discussion, though there continued to be general interest in developing a system to account for investigatory protocols. The ASBMT Quality Outcomes Committee has specific interest in this topic, and will deliberate a proposal to bring to the CIBMTR for further consideration.

Recommendation:

- ASBMT Quality Outcomes Committee will use the comments derived from this meeting to propose a systematic method to approach investigatory HCT for further consideration.

**HOW SHOULD THE RESULTS OF THE CENTER OUTCOMES REPORT BE PRESENTED?**

***How should the report be presented to achieve greatest comprehension?***

Currently, the results of the center outcomes analysis are presented in a Transplant Center Directory which is available in a print version and online at <http://marrow.org> and <http://bloodcell.transplant.hrsa.gov>. Beginning in 2011, the print version will no longer be produced.

There was general consensus that the format of the current outcomes report is sufficient for the use of HCT centers, and can be augmented with univariate analysis provided independently to centers as supplemental tools to understand their performance. (See “*Making additional data available for center’s performance improvement efforts*”.)

However, feedback from patients indicates that the report in its current format is hard to understand. Limitations of the current publicly available data include complex language that is difficult for many patients to understand, information spanning multiple linked websites, and provision of raw numeric data that does not account for censoring or follow-up. These limitations may cause the currently available data to be unintentionally misleading to some audiences.

Several of the suggestions raised at the 2008 Center Outcomes were re-visited. Discussion centered around presentation of layered reports that offer a simple visual representation of centers performance, supported by more specific data about outcomes with explanations in patient-accessible language that include explanations of limitations and appropriate uses of the data. Links to national survival data for individual diseases and center volume data within the same website were considered important.

Recommendation:

- Develop a representative working group of patients, physicians, members of the OPA and website developers to consider new formatting and presentation of center outcomes information on the public website for the C.W. Bill Young Program. This group will present a final set of consensus recommendations to HRSA and the website working group for approval and implementation.

***Making additional data available for center's performance improvement efforts***

A major objective of the center outcomes reporting process is to provide transplant centers with performance measures and tools that facilitate quality improvement initiatives. To achieve this, CIBMTR has the opportunity to provide individual centers with information that increases their understanding of outcomes in specific groups of patients and places these data in context with normative national data. Such reports would be valuable, even though they would not contain multivariate adjustment or statistical comparisons. There were numerous suggestions for reports that would be useful for center directors.

Examples of enhanced reports for centers could include:

- Descriptive demographic and survival data by center, together with normative U.S. data to each center. Survival can be reported at several time points (e.g. 100 days, 6 months and one year), and demographic information can be stratified by transplant type.
- Provide a report with annual survival for each of the last five years for center directors in addition to the aggregate performance which is shown to the public.
- Survival estimates post transplant sorted by "risk" status such that high risk and standard risk are distinct.
- Create online calculator where the risk factors of a patient can be entered and the risk category is generated.
- Graphics to demonstrate observed vs. expected survival at individual HCT centers for standard risk and high risk HCT recipients.

Recommendation:

- CIBMTR will work to operationalize center-based univariate reports to provide contextual basis for the annual outcomes report and guide performance improvement efforts at individual transplant centers. Reports will be offered to centers together with 2010 outcomes reports, then further enhancements will be made based on feedback and resource availability.

*Date of latest revision: **March 11, 2011***

## Appendix A: Attendees of Center-Specific Outcomes Analysis Forum

Name	Organization	Representation
Claudio Anasetti, MD	H. Lee Moffitt Cancer Center	ASBMT / HCT Center
Helen Heslop, MD	Baylor College of Medicine	ASBMT / HCT Center
Thomas Joseph, MPS, CAE	ASBMT	ASBMT / HCT Center
Bob Krawisz, MBA	ASBMT	ASBMT / HCT Center
Peggy Appel, MHA	Northwest Marrow Transplant Program	ASBMT Quality Outcomes Committee
John Barrett, MD	NIH	ASBMT Quality Outcomes Committee
Roy Jones, MD, PhD	U.T.M.D. Anderson Cancer Center	ASBMT Quality Outcomes Committee
Jan Sirilla, RN, MSN	OSU James Cancer Hospital	ASBMT Quality Outcomes Committee
Patrick Stiff, MD	Loyola University Med Center	ASBMT Quality Outcomes Committee
Mukta Arora, MD, MS	University of Minnesota	CIBMTR
Dennis Confer, MD	NMDP	CIBMTR
Mary Eapen, MD	CIBMTR/MCW	CIBMTR
Parameswaran Hari, MD, MS	CIBMTR/MCW	CIBMTR
Mary Horowitz, MD, MS	CIBMTR/MCW	CIBMTR
Roberta King, MPH	NMDP	CIBMTR
Navneet Majhail, MD	University of Minnesota	CIBMTR
Willis Navarro, MD	NMDP	CIBMTR
Marcelo Pasquini, MD, MS	CIBMTR/MCW	CIBMTR
J. Douglas Rizzo, MD, MS	CIBMTR/MCW	CIBMTR
Stephen Spellman, MBS	NMDP	CIBMTR
Daniel Weisdorf, MD	University of Minnesota	CIBMTR
Robert Baitty, MPP	HRSA	Government Agency
James Bowman, MD	HRSA	Government Agency
Nancy DiFronzo, PhD	NHLBI	Government Agency
Brenda Emanuel, MPA	HRSA	Government Agency
Linda Griffith, MD, PhD	NIAID	Government Agency
Roy Wu, PhD	NCI	Government Agency
Lois Ayash, MD	Karmanos Cancer Institute	HCT Center
Stella Davies, MBBS, PhD	Cincinnati Children's Hospital	HCT Center
H. Kent Holland, MD	BMT Group of GA (Northside Atlanta)	HCT Center
Mitchell Horwitz, MD	Duke University BM&SCT Program	HCT Center
Michael Pulsipher, MD	University of Utah Primary Children's Medical Center	HCT Center
Thomas Shea, MD	University of North Carolina at Chapel Hill	HCT Center
Robert Soiffer, MD	Dana-Farber Cancer Institute	HCT Center
Douglas Taylor, MD, PhD	University of California, Davis Medical Center	HCT Center
Tim Hofer, MD	University of Michigan	Hospital Outcomes Reporting
John Klein, PhD	CIBMTR/MCW	MCW-Biostatistics
Brent Logan, PhD	CIBMTR/MCW	MCW-Biostatistics
Carol Doleysh, BS, CPA	CIBMTR/MCW	Other attendees
Kathleen Sobocinski, MS	CIBMTR/MCW	Other attendees
D'Etta Waldoch, CMP	CIBMTR/MCW	Other attendees
Paula Watry	CIBMTR/MCW	Other attendees
Kari Bailey, MBC	NMDP	Patient Advocate
Heather Houston	NMDP	Patient Advocate
Elizabeth Murphy, EdD, RN	NMDP	Patient Advocate
Nancy O'Connor	NMDP-Patient Services Committee	Patient Advocate

<b>Name</b>	<b>Organization</b>	<b>Representation</b>
Jim Omel, MD	NMDP-Patient Services Committee	Patient Advocate
Ruth Brentari	Kaiser Permanente	Payer Group
Stephen Crawford, MD	CIGNA Healthcare	Payer Group
Stephanie Farnia, MPH	NMDP	Payer Group
Carole Redding Flamm, MD, MPH	Blue Cross Blue Shield Association	Payer Group
Dennis Irwin, MD	OptumHealth	Payer Group
Adriana Mariani, RN, BSN, MPM	CIGNA LifeSOURCE Transplant Network	Payer Group
Wendy Marinkovich, RN, BSN, MPH	Blue Cross Blue Shield Association	Payer Group
Patricia Martin, RN, BSN	Anthem WellPoint	Payer Group
Aaron Schnell, BA	NMDP	Payer Group
Ted Gooley, PhD	Fred Hutchinson Cancer Research Center	Statistical Consultant

## References

- <sup>1</sup> Sorrow ML, Maris MB, Storb R, Baron F, Sandmaier BM, Maloney DG, Storer B. **Hematopoietic cell transplantation (HCT)-specific comorbidity index: a new tool for risk assessment before allogeneic HCT.** Blood 106:2912-2919, 2008.
- <sup>2</sup> Angela R. Smith, Navneet S. Majhail, Margaret L. MacMillan, Todd E. DeFor, Sonata Jodele, Leslie E. Lehmann, Robert Krance, and Stella M. Davies. **Hematopoietic cell transplantation comorbidity index predicts transplant outcomes in pediatric patients.** Blood First Edition Paper, prepublished online January 12, 2011; DOI 10.1182/blood-2010-08-303263.