Transplant Center-Specific Survival Data: Guidelines for Publicizing Results

Purpose of this document:

Often, transplant centers wish to share CIBMTR® (Center for International Blood and Marrow Transplant Research®) center-specific survival data with media and the public. This document will provide consistent guidelines for interpreting and sharing results.

Background

Each year—as part of the federally authorized C.W. Bill Young Cell Transplantation Program—CIBMTR® (Center for International Blood and Marrow Transplantation®), a research collaboration between NMDP® and the Medical College of Wisconsin, conducts an analysis of survival data for U.S. transplant centers performing allogeneic transplants. These data represent first allogeneic transplants performed with blood stem cells from related or unrelated donors.

- These reports provide
 - (1) An **overall risk-adjusted analysis** indicating whether one-year survival is as expected, above expected or below expected for each specific transplant center compared to an average transplant center in the United States.
 - (2) A more **specific analysis** with statistics representing patient survival rates, number of overall transplants performed and number of transplants by patient's age, disease type and stage.
- These reports are available to patients and the public through the NMDP Transplant Center Directory and can be viewed by visiting BeTheMatch.org: https://bethematch.org/tcdirectory/search
- The methodology for these reports is available on CIBMTR.org: https://cibmtr.org/CIBMTR/Resources/Summary-Slides-Reports/Center-Specific-Survival-Analysis-Methodology

How to Interpret and Describe These Reports

These reports should <u>not</u> be used to compare one year survival rates between transplant centers. Additionally, survival rates should only be compared to the confidence limit surrounding the center's expected survival - indicating a transplant center's results compared to expectations for that center's patients.

For example: An observed one-year survival rate of 74 percent at one transplant center (Center C) is not inherently better performance than a survival rate of 55 percent at another transplant center (Center A), if both centers' observed survival falls within the same expected survival confidence limit (as expected, above expected, below expected). An observed one-year survival rate of 63 percent (Center B) that is 'below expected' is not better performance than a survival rate of 55 percent (Center A) that is 'as expected'. An observed one-year survival rate that is 'above expected' (Center D) indicates better outcomes than a survival rate that is within the expected range.

	# Patients	Actual Survival	Expected Range		Comparison to
			Lower	Upper	Expected
Center A	207	55%	52%	63%	0 / As
Center B	233	63%	66%	77%	-1 / Below
Center C	317	74%	65%	75%	0 / As
Center D	266	74%	61%	72%	+1 / Above

Communicating Transplant Center Results

When drafting news releases and other public communication about these reports, please consider the following language guidelines:

- As noted above, these reports are not meant to be used to compare transplant centers against each other. Therefore, the following language is not an appropriate interpretation of the results presented in the report:
 - Referring to a transplant center as "the best/better/#1" based on this report.
 - o Indicating that a transplant center performed "better than ## other transplant centers."
 - Using specific statistics to compare transplant centers. For example, "[Insert Transplant Center Name] achieved a one-year survival rate of 70 percent compared to 68 percent at [Insert Transplant Center Name]."
- The report does illustrate which centers are performing at, above and below expectations.
 Examples of statements that are an appropriate interpretation of the results presented in the report are as follows:
 - "[Insert Transplant Center Name]'s performance on one-year survival is better than expected [or above the expected survival rate] compared to similar patients transplanted in the U.S."
 - "[Insert Transplant Center Name] has performed better than expected for the last several years."
 - "[Insert Transplant Center Name] is one of ## U.S. transplant centers that performed better than expected during the evaluation years represented in this report."
- Sharing of individual center-specific statistics is at the center's discretion, For example:
 - "According to a national, multivariate report including the years 2019, 2020 and 2021, [Insert Transplant Center Name] achieved an overall one-year survival rate of 70 percent for patients receiving first allogeneic transplants."
- These reports do <u>not</u> indicate any individual patient's likelihood of one-year survival, as every patient's experience is unique.

Questions and Review of Materials

Please feel free to share any media materials that include information from these reports with the NMDP media team for courtesy review prior to distribution.

If you have any questions about these guidelines, or you are developing a news release or other materials for distribution, contact the NMDP media team at media@nmdp.org.