

**Joint Traumatic Brain Injury Model System, Spinal Cord
Model System, and Burn Model System
National Data and Statistical Centers**

Model System Guidance Document #1: Harmonization of Follow-up Rates

Introduction:

This document applies to all Model Systems (TBI, SCI, and BMS) and provides an overview of the NDSC discussions about harmonization of follow-up rates across the three systems.

Purpose:

Comparison of follow-up rates across Model Systems.

Guidance:

Each Model System uses a slightly different formula to compute follow-up rates. This guidance examines the differences that result from the different formulas and provides recommendations for comparing the follow-up rates across Model Systems.

I. Calculations:

- a. Each model system NDSC (TBI, SCI, and BMS) calculated their follow-up rates in three ways, corresponding to the three slightly different ways in which the model systems calculate follow-up rates:
 - i. **BMS:** The numerator is the number of records with “some assessment done” for the designated time-point and quarter that were collected within the data collection window. The denominator is the number records with of windows closed for that time-point, quarter, and site. The denominator is adjusted by removing those with a designation of “died”, “unable to test/med prob”, “withdrew”, “incarcerated” and “still in hospital.”
 - ii. **SCI:** The numerator is the number of records marked as “followed” in the designated time-point. The denominator is the total number of records followed plus the total of records marked as “missing” (no Form II entered) and “lost”. The denominator does not include “incarcerated,” “withdrawn,” “recovered”, “deceased” and “ID unknown”. Very rarely a patient is still in acute hospitalization on their 1st Anniversary, in those cases, a Year 2 replaces the Year 1 (neither Year 1 nor Year 2 are included in the rate).
 - iii. **TBI:** The numerator is the number of records marked as “followed,” “incarcerated,” and “deceased” (only those records newly marked as deceased). The denominator is the number of records with windows closed at a point in time. The denominator is adjusted by removing those cases whose center was not funded to conduct interviews,-“old” deaths” and “old” withdrawals.
 - iv. **Comparison of Rates:** See Table 1, below, for a detailed review of the difference in rates across systems.

- v. **Similarities and Differences in Calculations:** SCIMS and BMS calculate their follow-up rates in the same way except BMS includes the category “still in hospital” that is removed from the denominator. SCIMS does not include this category in its data collection. TBIMS includes records that are newly marked as deceased or withdrawn in it’s numerator, which BMS and SCI do not. However, as evidenced by the numbers in Table 1, this difference does not lead to marked differences in follow-up rates.

II. Results

- a. As seen in Table 1, the differences in the rates are very small (mean: 0.7%; range: 0.0%-3.4%). The NDSCs discussed these differences and decided that:
 - i. Each MS will continue to calculate follow-up rates as they have done so in the past to ensure continuity and historical comparison within each system.
 - ii. Because the differences across systems are very small, comparisons of the follow-up rates among the Model Systems are valid in spite of small differences in formulas used to compute follow-up rates.

History:

Review schedule:

At least every 5 years.

Table 1. Comparison of Rates by Calculation Method:

	TBI	SCI	BMS
TBI*			
Year 1	89.4%	91.0%	91.0%
Year 2	87.4%	87.9%	87.9%
Year 5	91.3%	91.9%	91.9%
SCI**			
Year 1	89.3%	88.7%	88.7%
Year 5	82.3%	79.9%	79.9%
Year 10	78.9%	75.5%	75.5%
BMS*			
6 months	78.1%	79.6%	79.6%
Year 1	82.9%	83.3%	83.3%
Year 2	76.1%	77.1%	78.0%

Note: Calculations utilize data collected with follow-up windows closed between 1/1/2018-12/31/2018