

Burn Model System National Data and Statistical Center Data Collection Guidance

Introduction

Since 1994, the Burn Model System (BMS) has been collecting data on long term outcomes of burn survivors. The BMS identified important domains to include in the data collection through new measures and existing publicly available measures.

The BMS make their data collection forms public in order for external researchers to benefit from the BMS' years of discussion and experience with the data collection forms. They provide the following guidance for researchers, clinicians or other entities interested in using the BMS data collection forms for their data collection.

If you are interested in a formal, BMS-approved collaboration, see SOP #611, located online at the webpage: <https://burndata.washington.edu/standard-operating-procedures>. If you are interested in replicating the data collection of the BMS, following BMS procedures but have no interest in a formal, BMS-approved collaboration, please refer to the following guidance:

Collecting & Coding Data

1. The BMS Data Collection forms (i.e., questionnaires) are located online at <https://burndata.washington.edu/about-bms> and include questions for data to collect from burn survivors at hospital discharge and at follow-up time-points. Please note, the discharge and follow-up forms have different version for use with adults, pediatric self-report, and pediatric proxy (i.e., a report by a parent or care giver). These forms are available in English and Spanish, and the Spanish versions are fully certified.
2. The BMS collect follow-up data at hospital discharge, 6-months post-injury, 12-months post-injury, 24-months post-injury, and every 5 years post injury¹.
3. The BMS Standard Operating Procedures (SOPs) provide specific information about BMS inclusion and exclusion criteria for participants (SOP #101), guidelines for participant recruitment and consent (SOP #102), follow-up of participants (SOPs #103 & #105), and data quality guidelines (SOP #104). These SOPs can be found at this webpage: <https://burndata.washington.edu/standard-operating-procedures>.
4. Coding of each data point, along with some information on scoring and guidance for data collectors, is provided in the BMS Data Dictionary, which can be found at the webpage <https://burndata.washington.edu/about-database> under the heading titled "For Researchers Interested in the Data."

Scoring Data

In recent years, the Burn Model System has moved toward the use of standardized,

¹ Post-injury date is calculated based on the burn date, not hospital consent date.

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publicly available measures, so that the instruments and scoring algorithms are accessible to all with no licensing fees. Below are links for more information about the main outcome measures collected by the BMS:

1. PROMIS-Global, PROMIS-29, PROMIS Itch, PROMIS-25, other PROMIS measures, and NIH Toolbox and NeuroQOL measures:
<http://www.healthmeasures.net/explore-measurement-systems/overview>
2. Satisfaction with Life Scale (SWL): <https://www.sralab.org/rehabilitation-measures/satisfaction-life-scale>
3. Community Integration Questionnaire Social Integration Subscale (CIQ SIC)
<https://www.sralab.org/rehabilitation-measures/community-integration-questionnaire>
4. Post-Traumatic Check-List for DSM-5 (PCL-5).
<https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp>
5. Post-Traumatic Growth Inventory (PTGI):
https://www.emdrhap.org/content/wp-content/uploads/2014/07/VIII-B_Post-Traumatic-Growth-Inventory.pdf

Utilizing BMS Data

If you collect data using the BMS data collection forms and would like to combine your and the BMS's data for a study, there are two options to access the BMS data. These options are briefly described below. More information is available at:

<https://burndata.washington.edu/about-database>

1. Access the BMS Public Dataset, which is always available and contains data collected more than two years prior to the publication date. This dataset is located at: <https://burndata.washington.edu/about-database>
2. Request a customized dataset from the BMS. This option provides you with a dataset that includes only the variables you request for your specified years. This dataset option can include the most current data, and provides you with some technical assistance from the BMS NDSC.

Please note that any data you collect using BMS forms must not be publicly identified as BMS data. In any publications that merge BMS's data with non-BMS entity's data, acknowledgement of NIDILRR funding is not permitted except where those data collected by the BMS are clearly identified.

For any questions about the BMS data collection forms, the BMS public access dataset, or other enquiries, contact burndata@uw.edu.