

An estimated 1 million Americans sustain a burn injury each year, out of which 45,000 are hospitalized.

Severe burns are one of the most complex forms of trauma injury and often require longterm rehabilitation.

People with a burn injury can experience a range of physical and psychosocial concerns that can affect their ability to function.

The National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services sponsors the Burn Model Systems (See https://msktc.org/burn/modelsys tem-centers for more information).



This document is for people who have read the factsheet about the Burn Model System (BMS) National Database and are ready to submit a data request. Before you complete the data request form, please read the following information and examine the available resources listed here. This will ensure that there are no delays in receiving your dataset due to data requests that overlap with existing studies or research questions that cannot be answered using available BMS data.

## **Important Information About the Database**

- An **overview of the BMS**, including its purpose and data collection procedures (e.g., inclusion and exclusion criteria), can be found in this article by <u>Amtmann et al</u>.
- Please note that **major changes were made to the data collection surveys in 2015**. Many variables were added or removed from the BMS database at that time. Please refer to the BMS timeline (see below) for information about what changes were made. Other changes were made at other time points (e.g., 2006, 2022), but 2015 saw the most changes.
- The **pediatric dataset** has a number of unique characteristics. If you are planning to request pediatric data, please be aware of the following:
  - The majority of pediatric participants (55%) were enrolled at the Shriners Children's Texas at the University of Texas Medical Branch (UTMB) in Galveston. Most of these participants do not reside in the United States and traveled from Mexico to receive treatment at Shriners. These participants tended to have more severe burns than the pediatric participants who enrolled at other treatment sites. Shriners also paid for the care received for most of these participants rather than traditional insurance.
  - A significant percentage (20%) of pediatric participants speak Spanish as their primary language. This percentage is significantly higher (41%) for those participants who enrolled after 2015. Because follow-up was better for Shriner's participants from Mexico who received free care from Shriners, the majority (73%) of data from patient-reported outcome measures at follow-up, including PROMIS (Patient-Reported Outcome Measurement Information System) measures, were collected from Spanishspeaking participants.





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## To Do Before Requesting Data

- Several webinars are available to help you understand what kinds of data are collected by the BMS as well
  as how to formulate a research question and how to request a dataset. If you are new to using BMS data,
  please watch the two webinars on "Accessing and Using the BMS Database" (Part 1 and Part 2)
  prior to requesting a dataset, here: <u>BMS Webinars</u>. These can also be accessed by going to the website
  (https://burndata.washington.edu) and scrolling down on the homepage to the link that says Webinars.
- Before you request a dataset, you must ensure that your research question or hypothesis does not overlap with ongoing research studies. If it does overlap, your data request may be denied. You can find a complete list of ongoing research studies that use the BMS database here: <u>Publications in Progress</u>, or by going to the Publications tab of the website (<u>https://burndata.washington.edu</u>) and clicking on the "Publications in Progress" link.

## **Resources for Formulating Your Data Request**

- The BMS Timeline is an "at-a-glance," big picture summary of what scales and measures are available in the BMS Database and at what time points. This is the easiest way to determine if the variables you are interested in were collected at the same time and for a long enough period to have adequate data (i.e., sample size) to answer your research question. If the timeline shows that the measures you are interested in were only collected for a few years, then you may want to ask the data center if there are adequate data prior to submitting a data request (by emailing <u>burndata@uw.edu</u>). Access the timeline by clicking here (pdf file). You can also access the timeline by going to the website (<u>https://burndata.washington.edu</u>) and clicking on the Access BMS Data tab. Scroll down to the section titled "What is in the Database" and click on the hyperlink there.
- The data dictionary contains specific information about the variables collected by the BMS including their specific wording, response choice and coding, time points collected, and method of data collection. If you require this level of information about the exact versions of items or scales used by the BMS, please refer to the data dictionary, which can be accessed here: <u>BMS Data Dictionary</u> (Excel file), or by going to the website (<u>https://burndata.washington.edu</u>) and clicking on the Access BMS Data tab. Scroll down to the section titled "How to Request BMS Datasets" and click on the hyperlink to the data dictionary.

## Source

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