BURN MODEL SYSTEM

BMS

ADVANCING RECOVERY THROUGH KNOWLEDGE

Using Data from the Burn Model Systems National Database

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) supports the collection of data from participants in the Burn Model System (BMS) Centers Program.

The BMS Centers have made a substantial long-term contribution to establishing and maintaining the BMS National Database.

The Burn Model System National Data and Statistical Center currently supports the four model system sites funded by NIDILRR shown below:*

- **Boston-Harvard Burn Injury Model System, Boston, MA**

- **North Texas Burn Rehabilitation Model System, Dallas, TX**

- **Southern California Burn Model System, Los Angeles, CA**

- **Northwest Regional Burn Model System, Seattle, WA**

*Johns Hopkins was funded from 1994 to 2012. University of Colorado was funded from 1994 to 1997. University of Texas Medical Branch was funded from 1998 to 2022.

Introduction

This fact sheet serves as a quick reference on the policies associated with accessing and using data from the Burn Model Systems (BMS) National Database. This is intended for the public and those in the general scientific community who do not receive federal funding to collect data for the BMS.

What Is the BMS National Database?

The Burn Injury Model Systems National Database is a prospective, longitudinal, multicenter research study that examines health, functional and psychosocial outcomes following a burn injury for nearly 5,000 adults and 2,000 children. It contains data from a unique, well-characterized population of individuals with moderate to severe burn injury. Institutions across the country receive federal funding to learn more about outcomes after burn injury. For further information, visit our website at https://burndata.washington.edu/.

The BMS welcomes the use of the data by non-BMS researchers who share our goal of improving the lives of burn survivors.

What Are the Two Types of BMS Data Access?

Annually Published Public Access

The Public Dataset is published annually and contains data collected up to two years prior to its publication date. Data are stripped of all HIPAA-defined identifiers, including names, geographic subdivisions smaller than a state, elements of dates (except year) related to an individual, telephone numbers, fax numbers, email addresses, social security numbers, and medical record numbers.

Custom Data Access

A Custom Data Set includes all available data (i.e., all data available at the time of request), and is available free of charge to researchers with specific hypotheses who might want BMS input or collaboration.

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What Is the Difference Between Annually Published and Custom Datasets?

The Annually Published Dataset includes:
- **All** BMS data available except identifiers
- Data collected up to 2 years prior to the publication date, i.e., data in the dataset is **older** than 2 years before the publication date

A Custom Dataset includes:
- Only variables you request and are necessary to answer your research question(s)
- Most recent data available at the time of request

Both datasets include:
- Contain de-identified data
- Require users to agree to a data use agreement

How to Request BMS Datasets

Annually Published Public Dataset
1. Go to https://burndata.washington.edu/about-database;
2. Click on the hyperlink under the heading "Public Access";
3. Agree to the terms of data use and download the dataset with the provided link.

Custom Dataset:
1. Formulate your research question(s) and hypotheses. Review the list of papers already published (https://burndata.washington.edu/pubs) or in progress (https://burndata.washington.edu/publications-progress) to make sure your research questions have not already been addressed.
2. Review the variables in the database. Pay close attention to whether the variables you are interested in are available at the time points of interest;
3. Download and fill out a Data Request and Use Agreement Form from https://burndata.washington.edu/sites/burndata/files/files/DataAgreementForm.pdf. Email the completed forms to the BMS NDSC at burndata@uw.edu.
4. The BMS reviews the scientific purpose and scientific overlap with existing projects and approves the request (typically within 2 weeks).
5. Once approved, the BMS NDSC will provide a de-identified dataset and assist with any questions you have about the dataset free of charge.
6. Provide annual updates on progress of the project, and an updated anticipated completion date.

Resources available to you at https://burndata.washington.edu/about-database:
- Overview of available variables (pdf download)
- Database Data Dictionary with detailed information on all variables: (Excel file download)
- A BMS Database Introduction PowerPoint presentation

Source

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