Using the Burn Model Systems National Database

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, *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 establish and maintain the BMS National Database.

The BMS 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

The North Texas Burn Rehabilitation Model System, Dallas, TX

Pediatric Burn Injury Rehabilitation Model System, Galveston, TX

Northwest Regional Burn Model System, Seattle, WA

*Johns Hopkins University was funded from 1997– 2012.

*University of Colorado Health Sciences was funded from 1993-1997.

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 those in the general scientific community who are not a funded data collection site 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 for almost 4,000 adults and over 2,000 children. The BMS National Database consists of common data elements from a unique, well-characterized population of individuals with moderate to severe burn injury. These data are collected by institutions across the country to learn more about outcomes after burn injury. For further information, visit our website at http://burndata.washington.edu/.

Who Can Use This Database?

The BMS National Database welcomes the use of the data by external researchers who share our goal of improving the lives of burn survivors. Anyone from the scientific community who wishes to use data from the BMS National Database can use this database free of charge.

Policies and Procedures for Obtaining Data From the BMS National Database

Before Requesting Access

Before requesting access review the variables available in the database to decide if the database includes the data you are interested in using. Also, please review the list of papers already published or in progress to make sure you do not duplicate the efforts of another researcher.

Use these links to learn more about the BMS database:

- Publications that analyzed the BMS Database (webpage)
  http://burndata.washington.edu/pubs
- Research studies in progress (webpage)
  http://burndata.washington.edu/publications-progress
- Overview of available variables (pdf download)
  http://burndata.washington.edu/sites/burndata/files/files/Overview-Current-Past-BMS-Variables(1).pdf
- Database Data Dictionary with detailed information on all variables:
  http://burndata.washington.edu/sites/burndata/files/files/BurnModelSystem_CurrentDataDictionary_March2018(1).xlsx

How To Request Data

The following procedures have been designed to be simple and invite participation by external researchers while maintaining the integrity of the data and the confidentiality of the participants.

1. Complete a Data Request and Use Agreement Form, available here (pdf download):
   http://burndata.washington.edu/sites/burndata/files/files/DataAgreementForm.pdf
2. Email the completed form to the BMS National Data and Statistical Center (NDSC) at **burndata@uw.edu**.
3. The NDSC will share the form with the BMS Project Directors for their review. The NDSC and Directors will review the scientific purpose and scientific overlap with existing approved projects.
4. The BMS project directors will have 10 working days for comments; the NIDILRR BMS Program Manager will make a final decision regarding approval of the proposal with feedback from the NDSC and BMS Project Directors.
5. Once approved you will work with the BMS NDSC to specify the variables to be included so that an appropriate de-identified dataset can be provided to you. **The NDSC will provide a de-identified dataset and assist with any questions you have about the dataset free of charge**. You may also request that the NDSC run the analyses. However, in this case the NDSC will require reimbursement from the requestor for the time and resources utilized to conduct such analyses. Please contact the NDSC for more information regarding reimbursements rates and details if this is desired.
6. Applicants have an option to propose or request a BMS researcher who is familiar with the data, measures and the data collection methods as a collaborator/consultant.

During Analysis

Once you have access to the data you will need to provide annual updates to the BMS NDSC, including the name of the Principal Investigator (PI), title of the project, progress on the project, and an updated anticipated completion date. If the project is not completed or moving forward with significant progress by three years after the approval date, other researchers will be allowed to address the same study aims using data from the BMS National Database.

Publication Policies When Using the National Database

1. At no time should a researcher who has been given access to the data attempt to identify individual patients.
2. All manuscripts should accurately describe data collection methods for the BMS National Database.
3. Any dissemination of study findings (including manuscripts, posters, and presentations) should include the appropriate acknowledgment (cite the appropriate SOP).
4. The PI must submit manuscripts to the BMS NDSC for administrative review at least four weeks before submission for publication.
5. The PI must apprise the BMS NDSC of the acceptance or rejection of manuscripts, abstracts, and presentations.
6. The PI must provide the NDSC with the URL and complete citation for any published manuscript, abstract, or presentation using the BMS National Database, when available.

Violation of the Data Use Agreement

If users violate the agreement, they should take corrective action as soon as they discover infractions. If users willfully violate the agreement, NIDILRR and/or NDSC may revoke current and future access to the BMS National Database.

Fraudulent Use of Data

Should the BMS Project Directors or the BMS NDSC discover an attempt to publish data that were fraudulently obtained, immediate steps will be taken to end the violation. This may include discontinuing the user's data access, reporting the violation, and reporting scientific misconduct to the violator's institution, relevant professional organizations, and/or scientific institutions.