

*The National Institute on Disability and Rehabilitation Research (NIDRR) 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 National BMS Data Center currently supports the four model system sites funded by NIDRR 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 was funded from 1993–2012.*

## 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. Topics covered include:

- What Is the BMS National Database?
- Policies and Procedures for Obtaining Data From the National Database
- Publication Policies When Using the National Database
- Failure To Follow Policies and Procedures

## What Is the BMS National Database?

The Burn Injury Model Systems National Database is a prospective, longitudinal, multicenter research study that examines functional and psychosocial outcomes following burns for over 3000 adults and almost 2000 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 a burn injury. For further information, visit our Web site at <http://burndata.washington.edu/>.

## Policies and Procedures for Obtaining Data From the National Database

### Who Can Use This Database?

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

### How Do You Request Data?

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

1. Complete a Data Request and Use Agreement Form, available at <http://burndata.washington.edu/standard-operating-procedures> (under the link for Standard Operation Procedure #604, External Collaboration).
2. Email the completed form to the BMS National Data and Statistical Center (NDSC) at [burndata@uw.edu](mailto:burndata@uw.edu).
3. The NDSC will share the form with the BMS Project Directors for their review of Principal Investigator (PI) affiliation, scientific purpose, and scientific overlap with existing approved projects.

4. BMS project directors will have 10 working days for comments; the NIDRR BMS Program Manager will make a final decision regarding approval of the proposal with feedback from the NDSC and BMS Project Directors.
5. After approval, the PI will work with the BMS NDSC to specify the variables to be included so an appropriate de-identified dataset can be released to the PI.
6. Applicants have an option to propose or request a BMS researcher who is familiar with the data and the ways they were collected as a collaborator/consultant.

### 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 following acknowledgment of BMS and NIDRR support: “The Burn Model System National Database [or the ‘name of the Archived Collaborative Study dataset’] is supported by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) in collaboration with the NIDRR- funded Burn Model System (BMS) Centers. However, these contents do not necessarily reflect the opinions or views of the BMS Centers, NIDRR or the U.S. Department of Education.”
4. The PI must submit manuscripts to the BMS NDSC for administrative review at least two 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 a URL and complete citation for any published manuscript, abstract, or presentation using the BMS National Database, when available.

### Failure To Follow Policies and Procedures

#### Failure To Follow 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, NIDRR 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 obtained fraudulently, 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.

#### Source

This is a publication of the Burn Model Systems National Data and Statistical Center, University of Washington, Seattle, WA (Grant Number H H133A130004) and the Model Systems Knowledge Translation Center at American Institutes for Research, Washington, DC (Grant Number H133A110004). Both are funded by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC.