**Burn Model System**

**National Data and Statistical Center**

# STANDARD OPERATING PROCEDURE (SOP) #604

External Request for BMS National Database and Archived Collaborative Study

Datasets: Request and Data Use Agreement Form

*Note: This form should be used for requesting use of the BMS National Database or*

*Archived Collaborative Study Datasets by the general scientific community.*

**Purpose of use** (check all that apply):

[ ] Research

[ ] Other (specify):

**Dataset to be used** (check all that apply):

[ ] BMS National Database

[ ] Archived Collaborative Study Dataset (specify):

**Principal investigator’s name**:

**Principal investigator’s position**:

**Principal investigator’s primary institutional affiliation: Type and Name**

(check one):

[ ] Non-profit organization; Name:

[ ] For-profit organization; Name:

[ ] Government agency; Name:

[ ] Other (specify): Name:

**Principal investigator’s address**:

**Principal investigator’s email**:

**Collaborators’ names** (after each name, please include the collaborator’s primary institutional affiliation in parentheses):

**Today’s date**:

**Project start date**:

**Projected completion date**:

**Date last updated** (if applicable):

**Proposed Research**:

Provide a brief summary (no more than 4 pages) of the proposed work to be completed with these data. Please follow the format below:

Title of project Key words Background/Introduction Study aim(s)

Research hypotheses

Methods

Study sample

Primary outcome measures

Secondary outcome measures Covariates/confounding measures/variables

Data analysis plan

Sample size calculation (not required but suggested)

**Do you intend to link the BMS NDB with any other datasets**?

[ ] Yes

[ ] No

If so, please describe the data to be linked to the BMS National Database or Archived or Ongoing Collaborative Database data, and the linking procedures/techniques to be used:

a. Do you require any linking variables in the limited dataset? If so, please check those required and include justification of why variable is needed for the purposes of your study:

* \_\_\_ State Code
* \_\_\_ County Code
* \_\_\_ CensusTract
* \_\_\_ CensusBlock
* \_\_\_ Zip Code

**Do you need support from the BMS? If so, what kind of support?**

 [ ] Statistical support (this may involve expenses to be paid to the BMS NDSC. If you check this box, the BMS NDSC will work with you on the scope of work and any payment required).

[ ] Mentorship from BMS researchers (this will not involve any expense to you)

**IRB approval numbers and expiration dates** (not necessary for initial submission, but required prior to release of the data)

**Dissemination plan** (choose all that apply): [ ] Publication

[ ] Presentation

[ ] Other (specify):

**Data Use Agreement**

I (the PI named above) request access to data from the Burn Model System (BMS) National Database and/or the BMS Archived Collaborative Study Datasets for the purpose specified above and agree to the follow terms:

1. I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact, any of the subjects from whom these data were collected.

2. I will not further disclose these data beyond the uses outlined in this

Agreement and in my data request described above in this request.

3. I will promptly notify the BMS National Data and Statistical Center of any substantive changes to the proposed research project or of any new projects to be initiated with the requested data. Such notification will consist of a new

project description (i.e., the submission of a new *External Request for BMS* *National Database and Archived Collaborative Study Datasets: Request and*

*Data Use Agreement Form*). This notification will be sent via email to burndata@uw.edu.

4. I will require anyone on my research team who utilizes these data to comply with this data use agreement.

5. I will provide annual updates on the progress of this project to the BMS

National Data and Statistical Center by emailing the update to burndata@uw.edu

6. I will comply with any rules and regulations imposed by my institution and its Institutional Review Board (IRB) in requesting and using these data.

7. I agree that the use of the data for this request is limited to two years and

after such time a new request and data agreement form (*External Request for*

*BMS National Database and Archived Collaborative Study Datasets: Request and Data Use Agreement Form*) should be sent to the BMS National Data and

Statistical Center for re-approval by emailing burndata@uw.edu.

8. I will report any use or disclosure of the data not provided for by this

Agreement of which I become aware within 15 days of becoming aware of such use or disclosure by emailing burndata@uw.edu.

If I publish abstracts or manuscripts (papers) using data from the BMS National

Database or Archived Collaborative Study Datasets, I agree to the following:

1. I will describe the methods of data gathering used for the BMS data.

2. I will add the following acknowledgement to the published product:

“The Burn Model System National Database [or the ‘name of the Archived Collaborative Study dataset’] is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).  The contents of this (insert type of publication; e.g., book, report, film) do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government..”

3. I will submit manuscripts to the BMS National Data and Statistical Center for administrative review two weeks prior to submission elsewhere. This review is not intended to be scientific, but rather administrative to ensure that the terms of this User Agreement have been fulfilled and that the data collection methods for the BMS Centers have been accurately described. The BMS National Data and Statistical Center and the BMS Project Directors will maintain confidentiality of abstracts, manuscripts, and presentations. Manuscripts will be emailed for review to burndata@uw.edu.

4. I will apprise the BMS National Data and Statistical Center of acceptance or rejection of abstracts, manuscripts, and presentations by emailing burndata@uw.edu.

5. I will provide abstracts, manuscripts, and presentation citations to the BMS

1. National Data and Statistical Center upon acceptance by emailing burndata@uw.edu.I will provide the URL and complete citation for any published abstract, manuscript or presentation using BMS data to the BMS National Data and Statistical Center when available by emailing burndata@uw.edu

If I share the BMS NDB, I agree to the following:

1. BMS NDB should only be shared with other AUTHORIZED USERS.
2. Each and every person who will use the BMS NDB for the purposes of the study pertaining to this data use agreement will complete, sign and submit to the NDSC a duplicate version of this form, and agree to these Terms of Use to become an AUTHORIZED USER.
3. If the intended recipient of the BMS NDB data does not submit a duplicate request and agree to these Terms of Use, I will not give them access to the BMS NDB.
4. I will not share the BMS NDB with a person who is not an AUTHORIZED USER.
5. In the event that a person who is not an AUTHORIZED USER obtains the BMS NDB, I will promptly notify the NDSC of the data accessed and the person who received it.
6. There is no redistribution or sharing of the BMS NDB with anyone or any entity for any reason, except that required for journal publication or by research funding agencies. Journal editors or grant makers may, in certain circumstances, request a copy of the data on which a paper or report is based; in which case, I will notify the NDSC in writing prior to redistribution/sharing for this purpose

I understand that failure to abide by these guidelines will result in termination of

my current and future privileges to access data from the BMS National Database and Archived Collaborative Study Datasets. Should I try to publish data from the BMS National Database or Collaborative Study Datasets fraudulently or breach this Data Use Agreement, immediate steps will be taken to secure the breach or end the violation. This may include discontinuing the user’s data access and/or reporting

the violation, and reporting scientific misconduct to the violator’s institution and/or

relevant professional organizations and/or scientific institutions.

PI Signature Date