

**Burn Model System
National Data and Statistical Center**

STANDARD OPERATING PROCEDURE (SOP) #611

SOP #611	Title: BMS Approved Collaborative Relationships with External Partners	
Approved: BMS Project Directors	Effective Date: 6/9/2020	
Attachments:	Revised Date:	
Forms: None	Review Date:	
Review Committee: BMS Project Directors		

Introduction:

This policy addresses the conditions and considerations for approving non-BMS entities (i.e., institutions not funded by NIDILRR as a BMS center or BMS follow-up center) as BMS external Data Collection Partners to collect data on BMS variables and conduct analyses using combined BMS and external entity collected data.

Purpose:

To guide the process for establishing a formal BMS-approved collaborative relationship between the BMS and a non-BMS.

Scope:

All current BMS Centers, the BMS National Data and Statistical Center (NDSC), and non-BMS entities wishing to enter into formal data collection collaboration with the BMS.

Responsibilities:

All entities identified in the "Scope" statement will abide by this policy.

Policy:

In general, the following principles apply to all BMS-approved data collection collaborations with external collaborators, referred to from now on as Proposed Data Collection Partner (PDCP):

- 1) The NDSC gives highest priority to BMS-related work that is specified in its grant application.
- 2) All costs of housing and managing the PDCP's data, training the PDCP's data collectors, and implementing data quality procedures will be borne by the PDCP.
- 3) If the proposed collaborative relationship is of interest to the BMS Project Directors and NIDILRR, the BMS will engage in discussions with the PDCP that address the following issues:
 - i. The purpose of the proposed data collection collaboration.
 - ii. The BMS variables to be collected by the PDCP (if not all variables).
 - iii. The PDCP's access to burn survivors who meet BMS inclusion/exclusion criteria.

- iv. The process the PDCP will use to set up and manage the necessary databases to hold the data collected, including who will be responsible for the development, maintenance, quality, and security of the databases.
 - v. Data quality:
 - (a) Data collectors. Who will collect the PDCP's data? What expertise must data collectors have? What training will they receive? How, when, and where will this training occur?
 - (b) Data collected. What standards will be used to evaluate if the PDCP's data are of sufficiently high quality to be combined with the BMS data for the intended purposes? How will data quality be monitored over time? (For example, data verification, double data entry, variable checking—see SOP 104).
 - vi. Will the PDCP strive to meet BMS benchmark targets for enrollment rate (including minority group enrollment rate), follow-up rates and missing data rates? The benchmarks are laid out in SOP #606.
 - vii. The amount of PDCP staff time (FTE) dedicated staff for data collection and data quality assurance.
 - viii. The amount of funds the PDCP will contribute to supporting the NDSC's work (if any) on behalf of the Proposed Data Collection Partner, e.g., housing the data, managing the data, training, technical assistance.
 - ix. The anticipated use of the resulting datasets, for example, specifications for when the PDCP may seek to combine their data with the BMS's data, and who will have access to the combined dataset.
 - x. How the PDCP will address potential overlap of participants enrolled by the BMS and those enrolled by the PDCP? If this is a possibility, what will be done to coordinate the duplicate enrollment so that it is not disadvantageous to the BMS and to prevent duplication of records?
 - xi. Participation in the BMS meetings/communications: will the Proposed Data Collection Partner join BMS teleconferences, and/or in-person meetings? Will the PDCP's leadership and staff be added to BMS listservs?
- 3) After these discussions, if all involved parties (PDCP, BMS NDSC, BMS Project Directors, NIDLRR) agree to proceed, then the PDCP will develop a proposal that addresses their strategies for each of these issues.
- 4) The desirability and feasibility of the proposed collaboration will be considered by NIDLRR, the NDSC, and BMS Project Directors. The extent of resources needed to carry out the partnership, especially with regard to the staff time of the NDSC, will be determined. NIDLRR, the NDSC, and the BMS Project Directors will then approve, ask for revision of, or decline the proposed collaboration.

Once the collaboration proposal (as discussed in #4, above) is approved, the PDCP will be considered a BMS-approved Data Collection Partner. This entity must: (a) enroll participants according to the BMS inclusion/exclusion criteria (or using inclusion/exclusion criteria that is coded such that it can be matched to the BMS inclusion criteria), (b) use the same data collection instruments as used by the BMS grantees for the

BMS National Longitudinal Database (NLDB) and/or module studies, and (c) conform to the agreed upon data quality procedures.

If the Data Collection Partner does not consistently meet the data quality standards within 2 years of the start of the partnership, the BMS approval or the partnership may be revoked.

Training requirements:

Data collectors at approved BMS-approved Data Collection Partner will go through the same BMS NDSC training procedures as BMS Center staff.

Compliance:

All persons identified in the "Scope" statement must comply with this procedure.

References:

None

History:

Review schedule:

At least every 5 years.