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National Institute on Disability, Independent Living, and Rehabilitation Research Burn Model System: Review of Program and Database

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Abstract

The Burn Model System (BMS) centers program was created in 1994 to evaluate the long-term outcomes of burn injuries. As part of this multicenter program, a comprehensive longitudinal database was developed to facilitate the study of a number of functional and psychosocial outcomes after burn injury. In this article, we provide an overview of the data collection procedures, measures selection process, and an overview of the participant data collected between 1994 and 2016. Surveys were administered during hospitalization and at 6, 12, and 24 months after discharge, and in the most recent funding cycle, data collection at every 5 years postinjury was added. More than 7200 people with burn injury were eligible to participate in the BMS National Longitudinal Database. Of these, >5900 (82%) were alive at discharge and consented to follow-up data collection. The BMS National Longitudinal Database represents a large sample of people with burn injury, including information on demographic characteristics, injury characteristics, and health outcomes. The database is publicly available and can be used to examine the effect of burn injury on long-term outcomes.

Keywords

Burn; Injury; Rehabilitation

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The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funds 3 traumatic injury model system centers programs: the Spinal Cord Injury Model System, the Traumatic Brain Injury Model System, and the Burn Model System (BMS). The programs share a common goal of improving long-term health and function, community living and participation, and employment outcomes of individuals with these injuries. Since its inception in 1994, the aim of the BMS centers program has been to "provide leadership in rehabilitation as a key component of exemplary burn care and to advance the research base on effective rehabilitation services for burn survivors."[1(p. 13,583)] The BMS centers program was originally funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. In 2014, the National Institute on Disability and Rehabilitation Research was moved from the U.S. Department of Education to the Administration for Community Living of the U.S. Department of Health and Human Services and was renamed the National Institute on Disability, Independent Living, and Rehabilitation Research. The BMS consists of 4 burn centers, a National Data and Statistical Center (NDSC), and a Model Systems Knowledge Translation Center (MSKTC). The BMS centers, located across the nation, provide comprehensive, multidisciplinary services and conduct research that contributes to the development of evidence-based burn injury rehabilitation.[1] This goal is accomplished through at least 3 funded research activities. First, BMS centers participate in the longitudinal BMS National Database (NDB) by collecting and contributing information on common data elements for a centralized BMS database. Data collected include preinjury history, demographic characteristics, burn characteristics, and treatment information as well as rehabilitation services and long-term outcomes such as depression, posttraumatic stress disorder, return to work, and community reintegration. Second, each BMS center conducts site-specific research, including the evaluation of interventions for pain and itch, the effects of propranolol on pediatric burn outcomes, and the effectiveness of return to work programs. Third, BMS centers collaborate with the MSKTC to provide research-based information to multiple stakeholder groups such as burn survivors and their families, clinicians, policymakers, and the general public. The products of these knowledge translation efforts include plain language translations of BMS journal articles, systematic reviews of burn literature, and fact sheets containing information on a range of topics relevant to survivors and their families, such as wound care, exercise, and return to work and school. In addition, consumer involvement in BMS activities is a hallmark of the program. Each grantee is required to ensure that the input of individuals with burn injury is used to shape BMS research and its knowledge translation products.

In this article, we review the BMS centers program with a focus on the BMS NDB. The last such review of the BMS was completed in 2007.[2] Here, we provide updated information on the BMS NDB, including a description of standard operating procedures (SOPs) for enrollment, data collection and data management, an overview of variables and measures currently used, and a report of participant characteristics.

BMS centers

The BMS centers program has been funded in consecutive cycles of 5 years each, beginning in 1994: 1994 to 1997, 1997 to 2002, 2002 to 2007, 2007 to 2012, and 2012 to 2017. At the

time of the writing of this article, the burn community is anticipating the release of the grant funding opportunity announcement for the 2017 to 2022 funding cycle. To be eligible for BMS funding, applicants must provide comprehensive care to individuals with burn injuries, including acute injury treatment and rehabilitation after hospital discharge, if indicated. The 4 BMS centers for the 2012 to 2017 funding cycle include the Boston-Harvard Burn Injury Model System, the North Texas Burn Rehabilitation Model System, the Northwest Regional Burn Model System, and the University of Texas Medical Branch/Shriner's Hospitals for Children-Galveston Burn Model System. Previously funded centers included the University of Colorado Denver Burn Model System (1994–1997) and the Johns Hopkins Burn Model System (1997–2012). The funding from NIDILRR is awarded on the basis of competitive renewals and peer reviews of all grant proposals submitted. NIDILRR publishes all request for proposals and abstracts for projects on its website (https://www.acl.gov/about-acl/about-national-institute-disability-independent-living-and-rehabilitation-research). In the recent 5-year funding cycle, BMS centers received an average of $375,000 (including indirect costs) per center per year. The BMS NDSC received $350,000 (including indirect costs) annually for 5 years.

BMS NDB

Data collection for the BMS NDB began in 1994 with the intention of providing a comprehensive and longitudinal record of health and community outcomes of burn survivors with more severe injuries. Other national databases collect data on the treatment and acute care period of the burn survivor, such as the American Burn Association's National Burn Repository database,[3] the National Trauma Data Bank,[4] and the Multicenter Benchmarking Study.[5] However, BMS is the only project that collects long-term outcomes on both pediatric and adult patients to better understand the relation between the injury, acute care, rehabilitation, and long-term functioning of people with burn injury. The National Burn Repository collects injury-specific information, but it does not extend data collection past the acute care period; similarly, the National Trauma Database collects information on acute care procedures and complications but does not follow trauma survivors after discharge from acute care. The structure and content of the BMS NDB has undergone changes in 23 years since its inception to improve the understanding of the life course of the burn survivor and to identify factors that affect outcomes, such as disability, distress, and social integration.

Data from both adults and children are included in the BMS NDB. Information is collected from medical records and self-report for adults; from medical records, self-report, and proxy report for children aged 8 to 18 years; and from medical records and proxy report for children aged 0 to 7 years. Self-report information on mental and physical health, rehabilitation services, depression, sleep, distress, and community participation has been collected at 6, 12, and 24 months postinjury since 1994. In the 2012 to 2017 funding cycle, data collection was expanded to include data collection every 5 years for the life span of the individual for the foreseeable future of the database. This long-term addition to the database will greatly aid in understanding challenges faced long after the burn injury.

The data in the BMS NDB are available to the entire research community, including researchers who are not directly involved in the BMS centers program. A procedure for

external researchers to request data has been developed, and further information including a detailed list of variables available and the research request form can be found online at http://burndata.washington.edu.

Eligibility criteria and enrollment processes

Staff at each clinical center approach all eligible patients, and patients are consented according to each center's institutional review board–approved processes. Eligibility criteria have changed since the inception of the program; a review of current and past eligibility criteria for the NDB is given in table 1. In general, the recruitment process involves providing the potential participant information on the BMS, including an explanation of the types of information collected and when follow-ups occur. Potential participants are informed that participation is voluntary and that all data provided is protected using standard data security measures, such as the fact that all data are stored on secured servers. The enrollment window closes after 30 days post-discharge, and potential participants who did not provide consent before that time are no longer eligible to participate.

Data collection procedures

After enrollment, data are first collected at discharge from acute care. Data are collected by an in-person or telephone interview or by an in-person or mailed paper-and-pencil survey. At the time of the writing of this article, piloting for online surveys is underway. Information on the burn injury, such as % total body surface area (TBSA) burned, % TBSA grafted, number of days on the ventilator, number of days in the inpatient rehabilitation unit (if applicable), and location of burn are gathered through medical record abstraction.

Participants are again contacted for data collection at 6, 12, and 24 months, and every 5 years postinjury. Because the time between time points is relatively long, the BMS uses multiple retention strategies to prevent dropout, such as regular contact with the participant through clinical center newsletters, birthday cards, and social media. When BMS centers are unable to contact participants, they use locating services and contact of friends or family members. Participants can withdraw from the study at any time, and participation is completely voluntary. Data collection methods for follow-up are the same as at discharge (ie, in-person interview, telephone interview, or in-person or mailed paper-and-pencil survey). The BMS has SOPs in place, including one that sets benchmarks for follow-up rates. The BMS procedures include in-depth strategies to reduce missingness and dropout to reduce selection bias in the database. Specific strategies include multiple follow-up attempts for missing data in received surveys, flexible interview appointments including nights or weekends, newsletters with research results and personal vignettes from burn survivors about the benefits of research, and use of locator services. If data collectors learn that a participant is deceased through a friend or family member contact or from a locating service, attempts are made to determine and verify the cause of death.

Data management

The BMS NDSC oversees the data collection by clinical centers, manages the data, and coordinates the activities of the BMS, including development and management of SOPs and facilitation of meetings. The University of Washington houses the BMS NDSC for the

2012 to 2017 funding cycle; previously, the BMS NDSC was located at the University of Colorado Denver (1997–2012).

The BMS NDSC manages the database and provides training, technical assistance, and statistical and analytical support for the centers. Currently, the BMS NDB data are managed using Research Electronic Data Capture (REDCap) electronic data capture tools[6] hosted at the University of Washington by the BMS NDSC. The BMS NDSC creates and maintains all project-related REDCap databases, whereas staff at each individual BMS center enter data collected from participants into the system.

Data quality procedures are performed quarterly, including double data entry of 10% of the records entered in the previous quarter, verification (comparing the online record with the paper form) of 10% of the records entered in the previous quarter, and variable checks, where the NDSC reviews data and flags any issues that need to be checked by the clinical centers (eg, a record is flagged if %TBSA grafted is higher than %TBSA burned). Quarterly reports on enrollment, follow-up, and missing data are also produced by the BMS NDSC; if any center is below a benchmark established by the SOP, they must develop an action plan aimed to improve the issue in question (ie, enrollment or follow-up rates, or missingness).

Variables and measures

Over time the variables and measures included in the BMS NDB have evolved, although in general data collected have always included items on preinjury history, injury characteristics and treatment, demographic characteristics, general health (physical, mental, social), and quality of life. The 2012 to 2017 funding cycle included an extensive review and revision of all measures collected by all centers for inclusion in the BMS NDB because of the added time points of every 5 years postinjury. An expert panel, including physicians and nurses treating people with burn injury, researchers and research staff, and measurement experts, discussed health and quality of life domains that should be assessed by the survey and how the data could best be collected (ie, by self-report or by proxy). Available self and proxy instruments measuring those domains were identified, and preference was given to standardized instruments that were developed with sound psychometric properties, validated in people with burn injury, based on item response theory (IRT), publicly available, and free for research use. Revised collection forms were piloted by the centers, and after an internal review by the data collectors, revised data collection forms were then tested using cognitive interviews with people with burn injury. The interviews provided information on the applicability, length of administration, and understandability of the forms.

Cognitive interviews have become an important method for the development of self-report questionnaires.[7] This method of qualitative data collection aims to identify or correct problems with items that are otherwise difficult to find, such as problems with instructions, wording, unclear questions, or too many/too few response options. Cognitive interviews conducted by the BMS involved asking participants to respond to items and then asking them to elaborate on how they selected the response to make sure items were meaningful, understandable, and functioning as intended.[8]

Cognitive interview participants were approached by clinical center staff and completed a separate informed consent. Targets for demographic and clinical characteristics of the cognitive interview participants were tracked to ensure that views of a broad spectrum of people with burn injury were represented. Based on the results of cognitive interviews, items were either modified, retained as drafted, or deleted and the data collection forms were finalized. The BMS NDSC has examined and monitored the revised forms for problems with understandability, length, missingness, and other issues during data collection.

Several measures added to the forms during this process include those that were developed and tested using IRT, such as the Patient-Reported Outcomes Measurement Information System (PROMIS).[9] Benefits of IRT-based measures are that they are brief, typically have minimal floor and ceiling effects, and allow for flexible administration methods, including general and custom short forms or dynamic administration by computer adaptive testing (CAT).[10,11] CAT reduces the number of items that need to be administered by targeting items to the specific respondent. As a result, time savings for a large survey can be substantial. The BMS currently administers short forms, but inclusion of the IRT-based instruments will facilitate CAT implementation in the next funding cycle. In addition to reducing respondent burden, the new forms prioritized measures that facilitate comparisons across populations and studies, including the use of measures from the National Institutes of Health Toolbox initiative.[12] By including IRT-based instruments that measure universal health domains (eg, physical function, depression, pain, sleep, social function) and are centered on the U.S. general population, researchers can compare health and function of burn survivors with those of other populations and compare results across treatment studies.

A summary of the current list of variables and measures included in the BMS NDB is given in table 2. At all time points, follow-up data includes information on what services were received by the burn survivor, such as physical therapy, occupational therapy, and operations and information on return to work, occupation, and number of hours worked, household income, suicidal ideation, and alcohol and drug use. Outcome measures recently added to the database after the most recent review include, but are not limited to, the 29-item PROMIS for adults, the 25-item PROMIS for children, the Neuro-QOL Stigma measure, the Posttraumatic Stress Disorder Checklist – Civilian, the Post-Traumatic Growth Inventory, and the Veterans Rand 12-Item Health Survey.

Participants in the NDB

Enrollment—Between January 1, 1994, and December 31, 2016, there were 7228 patients eligible to participate in the BMS NDB. Of these, 472 (6%) were not alive at discharge, 779 (11%) did not consent to the study, and 65 (1%) were not approached to participate. A total of 5912 patients (82%) consented to the study and were enrolled and consented to follow-up. Table 3 shows the enrollment by BMS centers.

Retention—During the course of the project, 72% of participants who enrolled (n=4191) provided at least some data at 6 months; 63% (n=3672) provided at least some data at 12 months, and 54% (n=3095) provided at least some data at 24 months. (Participants who were unable to be followed because of death, as determined by friend or family contact

or through a locating service, with an attempt made to verify with a death certificate or *International Classification of Diseases, Ninth Revision* coded cause of death, were removed from the denominator for these calculations.) However, in recent years the BMS has been successful in improving the follow-up rate. For the calendar year 2015, 86% (n=167) of the participants with a data collection window already closed provided data at 6 months, 83% (n=171) provided data at 12 months, and 81% (n=146) provided data at 24 months. For the recently initiated longer-term follow-up time points, there are 54% (398 of the 738 participant's data collectors attempted to locate for this time point) with data at 5 years and 48% (370 of the 765 participant's data collectors attempted to locate for this time point) with data at 10 years. Data collection for these longer-term follow-ups began in 2008 as a module project; therefore, the 5- and 10-year time points were originally collected on a subset of participants. Five-year follow-ups have only recently been expanded to the entire database; thus, we expect follow-up rates at every 5 years to improve over time now that the data collection effort has been expanded.

Participant characteristics—Descriptive statistics were calculated for both acute care variables such as TBSA burned and TBSA grafted as well as age, sex, and other demographic characteristics to show the makeup of the BMS sample. The percentages in the text below are based on the total number of participants with valid data recorded in the database. All data were summarized using STATA/SE version 13.[a] Table 4 provides a more detailed overview of the data reported below. The BMS publishes detailed annual reports that are available for download from http://burndata.washington.edu.

General demographic characteristics—The mean age of participants in the database is 30 years, and 71% are men. Between the ages of 5 and 65 years, 75% of the participants (n=3426) were men. Seventy-three percent of the participants were white, and 29% were Hispanic. The way race and ethnicity were recorded was changed in 2015 to align with the way data are collected by the U.S. census, which accounts for the missing data.

Injury risk factors—Eight percent of the participants (n=430) reported a preexisting physical disability and 10% (n=485) reported a history of mental health treatment in the past year. Eleven percent (n=551) had a self-reported history of alcohol abuse in the year before the injury and 9% (n=442) had a self-reported history of drug abuse in the year before the injury, as measured with the CAGE screening questionnaire.

Injury characteristics—In all participants, the mean TBSA burned was 24%, and 52% (n=3096) had a TBSA of <20%. Figure 1 presents the mean TBSA during the course of the project. The TBSA of the participants in the database has been variable over time, peaking in 2006 and decreasing slightly between 2006 and 2015. The mean TBSA grafted was 15.3%. Sixteen percent (n=920) also experienced inhalation injury, and fire/flame was the most common etiology of burn. Fifty-two percent of the injuries (n=3079) were nonintentional non–work-related burns, whereas 16% (n=952) were nonintentional employment-related burns.

[a]Supplier
STATA/SE version 13; StataCorp.

Injury treatment—The mean length of hospital stay was 29 days, and 10% of the participants (n=601) were treated in the inpatient rehabilitation unit for their injury. Figure 2 presents the mean length of stay during the course of the project. The mean hospital stay generally increased until its peak in 2011 and then decreased between 2011 and 2015. Figure 3 presents the mean length of stay by TBSA category. The length of stay increases as TBSA increases, with a sharp increase in the length of stay as TBSA reaches 80%. The mean number of days in the inpatient rehabilitation unit for this group of participants was 23±33 days (range, 1–541d). Twenty-eight percent of the participants (n=1677) needed ventilator assistance for breathing; of these, the mean number of days spent on the ventilator was 13±19 days (range, 1–200d).

Complications from injury—Eight percent of the participants (n=459) experienced amputation because of burn at the time of discharge. Three percent (n=139) had heterotopic ossification at the time of discharge.

Employment—A total of 69% of the participants (n=2253) between the ages of 18 and 65 years were employed at the time of injury. Eighty-five percent of the participants (n=961) between the ages of 5 and 18 years were going to school at the time of injury. Fifty-eight percent of the participants (n=917) over the age of 18 years who were employed at the time of injury reported employment at 6 months postburn, whereas 66% (n=922) were employed at 12 months and 71% (n=821) were employed at 24 months. The mean number of return to work days for participants (n=960) between the ages of 18 and 65 years was 158±218 days (range, 0–4386d).

BMS site-specific research

Twenty-five[13] publications have been generated using data from the NDB, and an additional 172 publications report results of BMS site-specific research. Detailed information on the outputs of the BMS, including publications and knowledge translation products, can be found in a recent article by Goverman et al.[13]

The interventions carried out as site-specific projects aim to improve the outcomes of pediatric and adult burn survivors and provide models for translational burn research. An overview of site-specific studies is given in table 5; additional recruitment and enrollment criteria for those site-specific studies are not listed, but further information can be found by accessing the websites listed in that table. The site-specific studies have provided the field with many important research findings. Examples include the following: (1) virtual reality is affordable, safe, and effective in treating contractures by reducing pain and improving range of motion[14]; (2) propranolol decreases muscle loss in children[15]; (3) older people (age, >75y) with burn injury require longer rehabilitation (≥6mo) to achieve maximal functional improvements[16]; (4) pain and insomnia have a significant effect on quality of life and return to work[17]; and (5) a scoring system developed to predict the development of heterotopic ossification.[18]

BMS knowledge translation

In partnership with the NIDILRR-funded MSKTC, the BMS centers contribute to the development of fact sheets and systematic reviews. Fact sheets are intended to educate patients about what to expect after burn injury; topics include, but are not limited to, pain, itch, scar management, exercise, and return to work and school. Between 2012 and 2016, there were 477,300 downloads of the fact sheets. In addition, in partnership with the MSKTC, the BMS has developed videos that describe the experiences of burn survivors on the topics of return to work and exercise. The BMS hosts a booth every year at the American Burn Association Annual Conference to disseminate the BMS publications and to invite collaborations with non-BMS researchers, clinicians, or entities. Further information and publicly available resources, such as the fact sheets, can be found at www.msktc.org.

Summary

Because burn injury survival rates have steadily improved,[19–21] the focus of burn research has shifted in the past decade to a greater emphasis on understanding the trajectory of recovery and long-term outcomes of burn survivors. For >20 years, the BMS centers program has sponsored research and knowledge translation activities, informed by burn survivors, with the goal of improving long-term outcomes for those with burn injury. The BMS NDB tracks outcomes of survivors of burn injury by collecting preinjury, discharge, and follow-up information, including factors that affect or predict rehabilitation or community participation outcomes. Analyses of these data by both BMS and non-BMS researchers are generating knowledge to inform treatment for burn survivors. Knowledge acquired through both BMS NDB research and BMS site-specific research is disseminated to patients, clinicians, and the burn research community via journal articles, fact sheets, videos, newsletters, websites, and events.

Study limitations

The BMS includes data collected by only 4 clinical centers, and the inclusion criteria focus on more severe burn injuries. As a result, data in the BMS NDB are not representative of the whole population of people with burn injury in the United States. However, compared to people with larger burns in the National Burn Registry, a 2007 study[22] found demographic and burn characteristics to be similar to the National Burn Repository data and provided evidence of the internal and external validity of the BMS NDB. Most of the data in the BMS NDB are collected by self-report. For some domains, such as pain, fatigue, and quality of life, self-report is the most appropriate way to collect the information. For others, such as sleep and cognitive function, self-report is not the preferred assessment, but objective measures, such as polysomnography or neuropsychological assessments, are beyond the scope of the program. It is therefore important to take into account how the data were collected when interpreting the results. Like all self-report surveys, the data collected by the BMS are vulnerable to recall, selection, and response biases. Selection bias occurs for many reasons, and some of them are strategic. The inclusion criteria set by the BMS introduce purposeful selection bias to focus on people with more severe burn injury. Recall bias occurs when participants may not accurately recall their experiences, feelings, or function that occurred, for instance, a year ago. This is especially true of questions about the period

before the burn injury. In addition, some questions in the BMS ask participants to attribute a symptom or function to their burn injury (eg, “Because of your burn, is it hard to work?”) that may be difficult, if not impossible, to do for people whose burn injury occurred years ago and/or for people with preexisting physical disabilities at the time of their burn.[9]

Response bias also reflects who decides to participate in the BMS and who continues their participation; during the course of the project, 82% of the patients eligible for the study elected to participate. There is some evidence that people with larger burns are more likely to stay in the study,[2] and it has been hypothesized that this is due to the fact that this population has more interactions with medical center staff, sees the need for learning more about long-term outcomes of burn survivors, and perhaps identifies as burn survivors in ways that people with smaller burns do not.

As with all longitudinal research, missing data and dropout represent important limitations of the BMS NDB. Missing data occur when a participant does not know an answer, misses a question, or cannot be found for follow-up data collection. The reasons these situations occur are multiple and complex and include geographical mobility of the population, death due to burn or non–burn-related causes, and individual procedures at each BMS center, including turnover of data collection staff.[2] In recognition of the validity threats that missingness and dropout introduce, the BMS continues to make significant efforts to minimize missing data and limit participant dropout.

Future directions

The BMS has started a new funding cycle in 2017. In this funding cycle, the BMS will continue to examine the measures and procedures that will advance the project toward brief, clinically meaningful, and psychometrically sound measurement. The BMS will conduct additional research studies to improve lives of burn survivors.

Conclusions

The BMS centers program represents an extensive effort to better understand the needs of burn survivors and their long-term rehabilitation outcomes in the areas of health and function, community living and participation, and employment.

The BMS is a rich resource for burn survivors and for the burn community as a whole. Burn researchers and clinicians benefit from the research results published in journal articles and from the data collected by the BMS. People with burn injury benefit from fact sheets that use approachable language to summarize experiences of other burn survivors and to provide evidence-based advice. The recent extension of data collection (every 5y throughout the life span) and the addition of important health domains will provide a more complete picture of long-term outcomes of burn survivors. The focus on universally applicable measures will facilitate comparisons across populations and studies. Finally, the addition of IRT-based instruments will position the BMS for dynamic administration via CAT, which can lower participant burden and increase participant retention to ensure the sustainability of the program.

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List of abbreviations:

BMS	Burn Model System
CAT	computer adaptive testing
IRT	item response theory
MSKTC	Model Systems Knowledge Translation Center
NDB	National Database
NDSC	National Data and Statistical Center
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
PROMIS	Patient-Reported Outcomes Measurement Information System
SOP	standard operating procedure
TBSA	total body surface area

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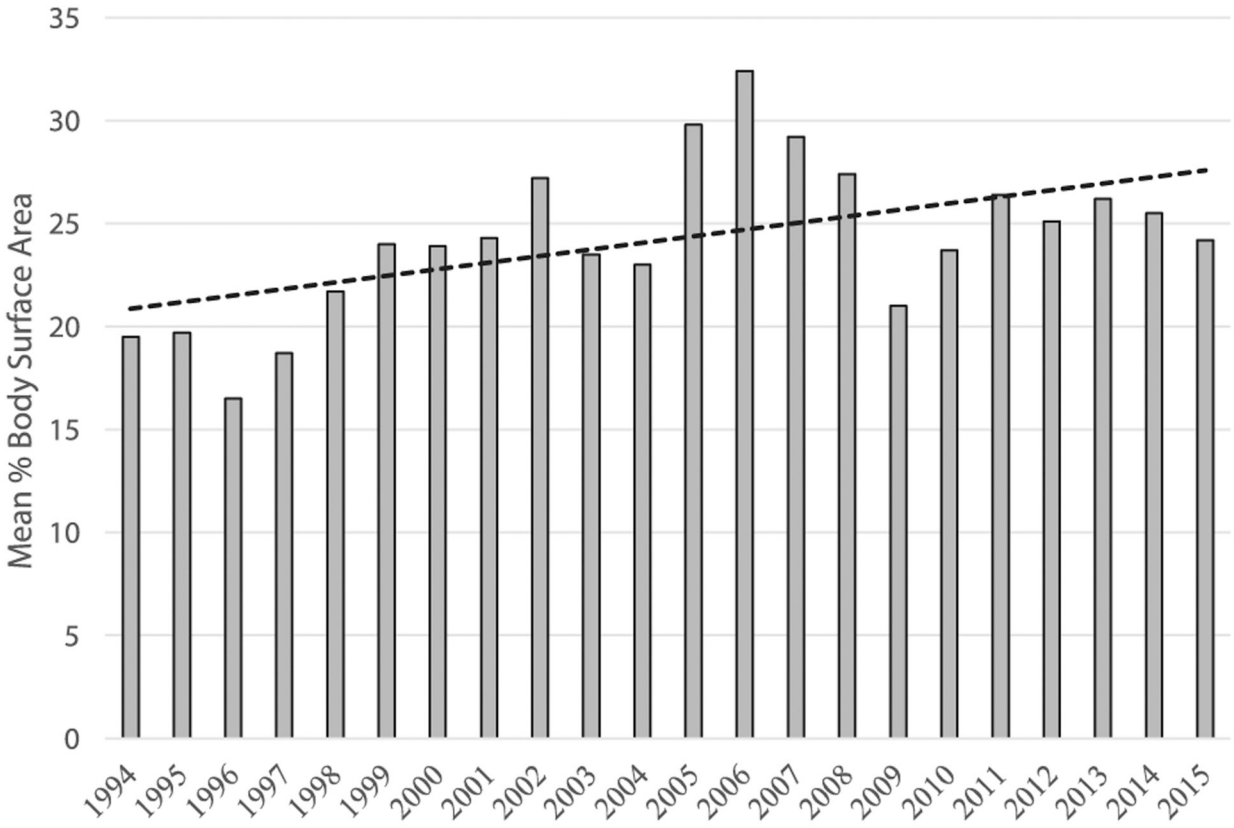

Fig 1.
Mean %TBSA burned in the participants in the BMS NDB by year (1993–2015).

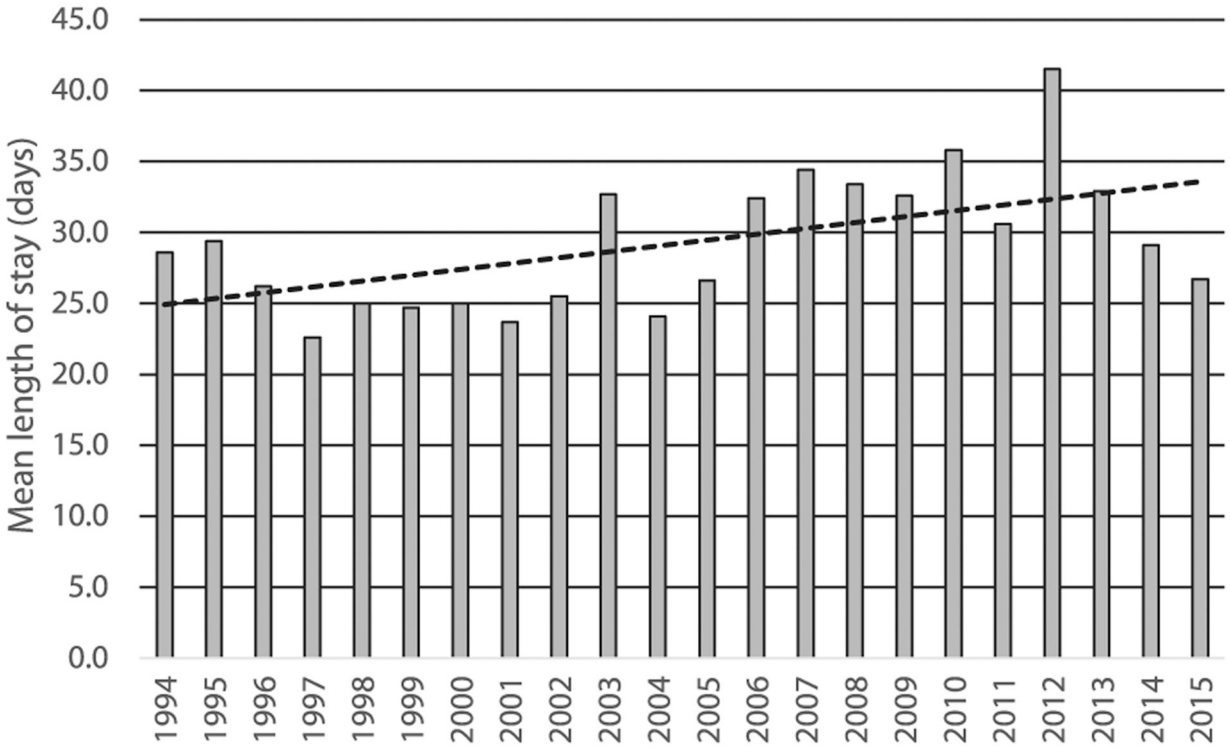

Fig 2.

Mean length of acute care hospital stay in the participants in the BMS NDB by year (1994–2015).

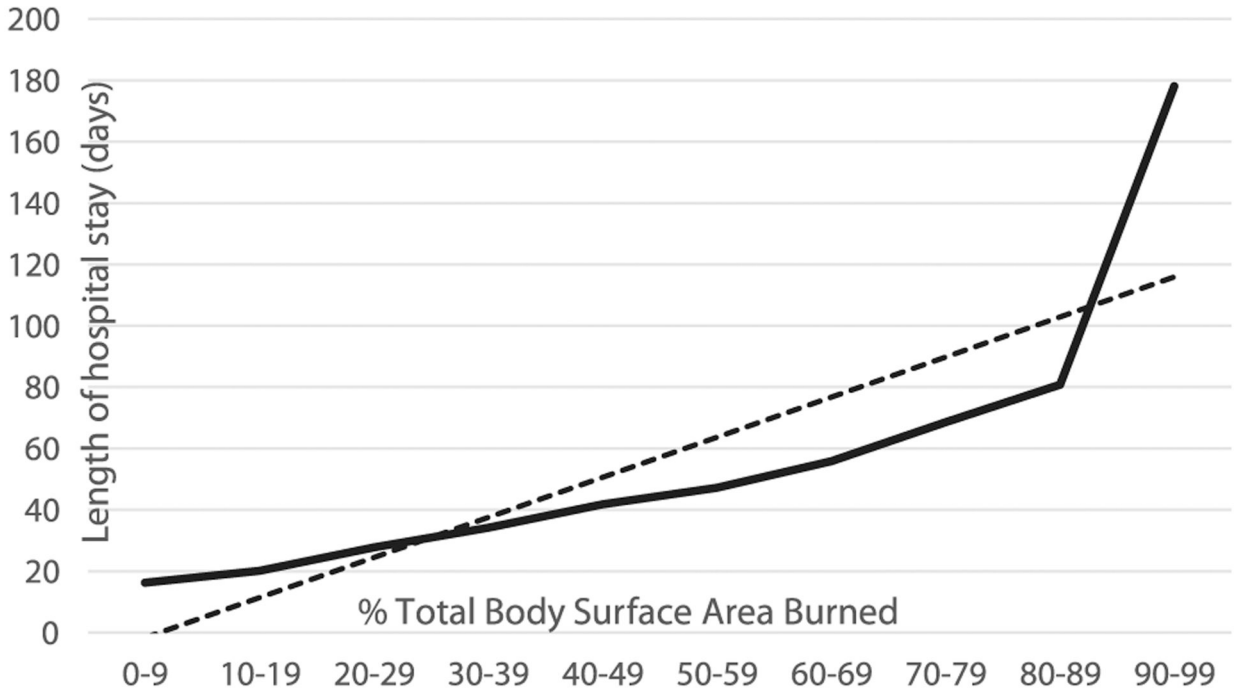

Fig 3.

Mean %TBSA burned in the participants in the BMS NDB by length of acute care hospital stay.

Table 1

Enrollment criteria for the BMS NDB

Before 2005	2006	2009
• Deep second- or third-degree burns • TBSA burned >10% in patients older than 50y • Deep second- or third-degree burns >20% TBSA in all other age groups • Deep second- or third-degree burns with serious threat to functional or cosmetic impairment that involves face, hands, feet, genitalia, perineum, or major joints • Third-degree burns >5% TBSA in any age group • Deep electrical burns including lightning injury; inhalation injury with burn injury • Circumferential burns of the extremity or chest	Before 2005 criteria with the following changes: • Burn surgery for wound closure required • TBSA requirements by age group were changed to TBSA >10% for those 65y or older and 20% for those aged 19–64y • Participants were also required to receive primary treatment at a BMS center with a reasonable expectation of follow-up treatment at a BMS center	2006 criteria with the following changes: • TBSA of ≥20% for those aged 0–64y • Exclusion of frostbite, toxic epidermal necrolysis, abrasions, necrotizing fasciitis, meningococcemia, and other skin disease

Table 2

Data collection domains and measures in the BMS NDB

Measure/Description of Items	Domain	Time Point Administered	New in the 2012–2017 Funding Cycle, Dropped, or Previously Administered?	Age Group (y) Administered To	BMS Specific or Standardized Measure?	No. of Items in Measure
Demographic Characteristic	Demographic characteristics (including income, marital status, living situation, work status, school status)	Discharge and all f/u	Some items are new, such as household income. Some have been previously collected, such as living situation and work status	Proxy: 0–17 Self-report: >13	BMS	25
Medical record abstraction form	Burn injury information	Discharge	Some items are new, such as MRSA presence/absence. Some have been previously collected, such as etiology of injury and disposition	All ages	BMS	45
Burn injury follow-up	Burn injury information	All f/u points, *not* pre or discharge	Some items are new, such as ability to drive. Some have been previously collected, such as physical or psychological therapy	Proxy: 0–17 Self-report: >13	BMS	15
Review of systems	Medical conditions	Collected at pre, d/c, and all f/u	New	>18	BMS	52
Child health conditions	Medical conditions	All f/u points, *not* pre or discharge	New	Proxy: 0–17 Self-report: 13–17	Standardized	19
Veterans Rand-12	Health-related quality of life	Collected at pre, d/c, and all f/u	New, replaces the SF12	>18	Standardized	12
29-Item PROMIS	Global health (including depression, fatigue, anxiety, peer relations, anger)	All f/u points, *not* pre or discharge	New	>18	Standardized	29
25-Item PROMIS	Global health (including depression, fatigue, anxiety, peer relations, anger)	All f/u points, *not* discharge or pre	New	Self-report: 8–17	Standardized	25
Community Integration Questionnaire	Community participation	Collected at pre and all f/u	Previously administered	>14	Standardized	6
PROMIS Peer Relationships	Community participation	All f/u points, *not* discharge or pre	New	Proxy: 8–17	Standardized	7
Suicidal ideation item from the Patient Health Questionnaire-9	Depression	Collected at pre, d/c, and all f/u	New	>18	Standardized	1
PROMIS Sadness	Depression	All f/u points, *not* discharge or pre	New	Proxy: 8–17	Standardized	4
PROMIS Depressive Symptoms	Depression	All f/u points, *not* discharge or pre	New	Proxy: 8–17	Standardized	6

Measure/Description of Items	Domain	Time Point Administered	New in the 2012–2017 Funding Cycle, Dropped, or Previously Administered?	Age Group (y) Administered To	BMS Specific or Standardized Measure?	No. of Items in Measure
National Institutes of Health Toolbox Sadness	Depression	All f/u points, *not* discharge or pre	New	Proxy: 3–7	Standardized	4
PROMIS Anger	Anger	All f/u points, *not* discharge or pre	New	Proxy: 8–17	Standardized	6
National Institutes of Health Toolbox Anger	Anger	All f/u points, *not* discharge or pre	New	Proxy: 3–7	Standardized	4
Neuro-QOL Stigma measure	Stigma/body image	All f/u points, *not* pre or discharge	New	>18	Standardized	8
Body Image	Stigma/body image	All f/u points, *not* discharge or pre	New	Proxy: 0–17 Self-report: 8–17	From BOQ	4
4-D itch (modified 5-D, distribution removed)	Itch	Discharge and all f/u, *not* pre	New	>18	Standardized	4 if the participant reports itch
Pain and itch	Itch	All f/u points, *not* discharge or pre	New	Proxy: 0–7	BMS	2
Itch (PROMIS pain items modified for itch by the BMS)	Itch	All f/u points, *not* discharge or pre	New	Proxy: 0–17 Self-report: 8–17	BMS	4
Posttraumatic Stress Disorder Checklist	Posttraumatic stress disorder	All f/u points, *not* discharge or pre	New	>18	Standardized	17
Child PTSD Symptom Scale	Posttraumatic stress disorder	All f/u points, *not* discharge or pre	New	Self-report: 8–17	Standardized	24
CAGE screening questionnaire for alcohol/drug use	Drug/alcohol/medication use	Collected at d/c and all f/u	Previously administered at d/c, now administered at f/u as well	>18	Standardized for alcohol; modified for drug use by BMS	8
Pain medication	Drug/alcohol/medication use	Collected at pre, all f/u points	New	Proxy: 0–17 Self-report: >13	BMS	12 pain medications to read and check if taking
Burn Specific Health Scale – Brief	Burn-specific health	All f/u points, *not* pre or discharge	New	>18	Standardized	40
Post-Traumatic Growth Inventory	Posttraumatic growth	All f/u points, *not* discharge or pre	New	>18	Standardized	10
Child PTGI	Posttraumatic growth	All f/u points, *not* discharge or pre	New	Self-report: 8–17	Standardized	10
PROMIS Physical Function Mobility	Physical function	All f/u points, *not* discharge or pre	New	Proxy: 8–17	Standardized	8
PROMIS physical Function upper extremity	Physical function	All f/u points, *not* discharge or pre	New	Proxy: 8–17	Standardized	8
Pediatric Evaluation of Disability Inventory Mobility	Physical function	All f/u points, *not* discharge or pre	New	Proxy: 0–7	Standardized	5

Measure/Description of Items	Domain	Time Point Administered	New in the 2012–2017 Funding Cycle, Dropped, or Previously Administered?	Age Group (y) Administered To	BMS Specific or Standardized Measure?	No. of Items in Measure
National Institutes of Health Toolbox General Life Satisfaction	Satisfaction with life/ positive affect	All f/u points, *not* discharge or pre	New	Proxy: 3–17 Self-report: 8–17	Standardized	4
National Institutes of Health Toolbox Positive Affect	Satisfaction with life/ positive affect	All f/u points, *not* discharge or pre	New	Proxy: 3–12 Self-report: 13–17	Standardized	4
Satisfaction with Life Scale	Satisfaction with life/ positive affect	Collected at pre and all f/u	Previously administered	>18	Standardized	5

Abbreviations: 4-D itch; 4-Dimension (4-D) Itch Scale; BOQ, Burn Outcomes Questionnaire; d/c, discharge; f/u, follow-up; MRSA, Methicillin-resistant Staphylococcus aureus; Child PTGI, Post-traumatic Growth Inventory for Children; SF12, 12-Item Short Form Health Survey.

Table 3

Enrollment and follow-up by BMS center

BMS Center	No. of Patients Enrolled	No. of Patients Followed*
Boston-Harvard Burn Injury Model System†	200	120
Johns Hopkins Burn Model System‡	807	395
North Texas Burn Rehabilitation Model System§	1746	1030
Northwest Regional Burn Model System§	1899	1600
University of Texas Medical Branch/Shriner's Hospital for Children Burn Model System‖	1246	979

*For the period October 1, 1993 to June 30, 2016, or for the funding period start date through June 30, 2016, where applicable. Some participants who were enrolled were not reflected in the last column because their follow-up data collection was not yet due.

†Funded from October 1, 2012, to present.

‡Funded from October 1, 1993, to September 30, 2012.

§Funded from October 1, 1993, to present.

‖Funded from October 1, 1997, to present.

Table 4

Demographic and clinical characteristics of the participants in the BMS NDB

Characteristic	Mean ± SD (Range)	n
Age (y)	30±21 (0.1–94.4)	5854
TBSA burned	24±20 (0–99)	5865
TBSA grafted	15±19 (0–99)	5330
Length of hospital stay (d)	29±33 (0–693)	5882
Characteristic	**%**	**n**
Sex: male	71	4209
Race		
Black	19	856
Asian	2	84
White	73	3260
American Indian/Alaskan Native	2	88
Native Hawaiian or Pacific Islander	0.5	21
Multiracial	1	55
Other	2	79
Ethnicity		
Hispanic or Latino	29	1687
Not Hispanic or Latino	71	4096
Etiology of injury		
Fire/flame	60	3459
Scald	16	941
Electrical	6	359
Contact with a hot object	4	247

Table 5

Examples of BMS site-specific studies

BMS Center	Website	Example of Site-Specific Studies
Boston-Harvard Burn Injury Model System *	www.bh-bims.org	Transcranial direct current stimulation for the relief of chronic pain and itch due to burn injury
Johns Hopkins Burn Model System †	Inactive	Effect of heat intolerance on exercise and physical function
North Texas Burn Rehabilitation Model System ‡	http://www.utsouthwestern.edu/education/medical-school/departments/physical-medicine/ntbrms/	Effect of heat intolerance on exercise and physical function
Northwest Regional Burn Model System ‡	http://burnrehab.washington.edu/	Randomized trial of hypnosis to reduce neuropathic pain and itch
University of Texas Medical Branch/Shriner's Hospitals for Children Galveston Burn Model System §	https://www.utmb.edu/sbhnidrr/	• Evaluation of the relation between acute stress disorder and posttraumatic stress disorder in children • Effect of combining an anabolic agent with a 3-mo outpatient rehabilitation program on the outcome

* Funded from October 1, 2012, to present.

† Funded from October 1, 1993, to September 30, 2012.

‡ Funded from October 1, 1993, to present.

§ Funded from October 1, 1997, to present.

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