

Burn Model System Summary Report

1994–2016

This report contains information, tables, and figures about the data contained in the Burn Model System National Database, collected from 1993 to 2016. The Burn Model System is funded by the National Institute for Disability, Independent Living, and Rehabilitation Research. This report was produced by the BMS National Data and Statistical Center.

2017



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Introduction

Severe burns are one of the most complex forms of traumatic injury. People with burn injuries often require long-term rehabilitation. Survivors of a burn injury often have a wide range of physical and psychosocial problems that can affect their quality of life. The Burn Model System (BMS) program began in 1994, with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), U.S. Department of Education. The BMS program seeks to improve, through research, care and outcomes for people with burn injuries. Its research programs are housed in clinical burn centers that provide a coordinated and multidisciplinary system of rehabilitation care, including emergency medical, acute medical, post-acute, and long-term follow-up services. In addition, and with funding from NIDILRR, each BMS center conducts research and contributes follow-up data to the BMS National Data and Statistical Center (BMS NDSC). The four BMS centers are

- Northwest Regional Burn Model System in Seattle, Washington;
- Boston-Harvard Burn Injury Model System in Boston, Massachusetts;
- Pediatric Burn Injury Rehabilitation Model System in Galveston, Texas; and
- North Texas Burn Rehabilitation Model System in Dallas, Texas.

Past centers included The Johns Hopkins University Burn Model System, University of Colorado Denver National Data and Statistical Center, and University of Colorado Denver Burn Model System.

The BMS NDSC supports the research teams in the clinical burn centers. It also manages data collected by the BMS centers on more than 5,900 people who have received medical care for burn injuries. The data include a wide range of information—including pre-injury; injury; acute care; rehabilitation; recovery; and outcomes at 6, 12, and 24 months after the burn injury. To be included in the database, the burn injuries of participants must meet several criteria (as of 2015):

- More than 10% total body surface area (TBSA) burned, 65 years of age and older with burn surgery for wound closure;
- More than 20% TBSA burned, 0–64 years of age with burn surgery for wound closure;
- Electrical high voltage/lightning injury with burn surgery for wound closure; or
- Hand burn and/or face burn and/or feet burn with burn surgery for wound closure.

In 2015, the BMS began a major initiative to collect data every five years after the injury and to collect new psychometrically sound, patient-reported outcome measures. On December 31, 2016, the database contained information for 3,757 adults (18 years of age and older) and 2,179 children (17 years of age and younger).

The BMS program disseminates evidence-based information to patients, family members, health care providers, educators, policymakers, and the general public. The BMS centers provide information in many ways: peer-reviewed publications, presentations at national professional meetings, fact sheets about different aspects of living with a burn injury, newsletters for patients on BMS research and center events, outreach satellite clinics for patients living in rural areas, and peer-support groups. The BMS program also

collaborates with the NIDILRR-funded Model Systems Knowledge Translation Center to promote the adoption of research findings by rehabilitation professionals, policymakers, and persons with burn injuries and their family members.

The BMS program establishes partnerships to increase the overall impact of research; information dissemination; and training of clinicians, researchers, and policymakers. Current partners include the [American Burn Association \(ABA\)](#) and the [Phoenix Society](#). Partnerships. Together, these partners help to ensure that NIDILRR-funded research addresses issues that are relevant to people with burn injuries.

Burn Model System Centers

Boston-Harvard Burn Injury Model System (BHBIMS)

The BHBIMS in Boston, Massachusetts, has a diverse and active group of burn injury clinicians and researchers as a part of its research team. BHBIMS is a collaborative research effort between Spaulding Rehabilitation Hospital, Massachusetts General Hospital, Shriners Hospital for Children–Boston, and Brigham and Women’s Hospital to improve care for burn survivors.

In addition to contributing to the national database, the BHBIMS conducts a site-specific study, Effects of Transcranial Direct Current Stimulation (tDCS) on Chronic Pain and Itch Following Burn Injury. This study is investigating tDCS, a noninvasive method of brain stimulation, to help relieve chronic pain and itch due to burn injury.

Project Director:

Jeffrey Schneider, MD

Project Coordinator:

Laura Simko

North Texas Burn Rehabilitation Model System (NTBRMS)

Parkland Health & Hospital System (PHHS) and University of Texas Southwestern Medical Center (UTSW) are internationally renowned for their top-quality comprehensive program of care, rehabilitation, and research involving children and adults who sustain major burn injury. The NTBRMS, housed within these hospitals, is a research team comprised of diverse staff.

The NTBRMS was instrumental in establishing the national database and has contributed detailed information on more than 1,500 participants since the BMS began. The center has two site-specific research studies: (a) the effect of heat intolerance on exercise and physical function and (b) the evaluation of a web-based, social skills training program for burn survivors. Each project links directly with the major life domains of the NIDILRR mission—health and function, and participation and community living.

Project Director:

Karen Kowalske, MD

Project Coordinator:

Radha Holavanahalli, PhD

Pediatric Burn Injury Rehabilitation Model System

Shriners Burns Hospital–Galveston, Texas, has worked for more than 40 years to develop new techniques to improve the outcomes of children who have major burns. Mechanisms are currently in place for the interdisciplinary care, rehabilitation, and follow-up of more than 300 children who have acute burns. The population of patients who have burns includes persons from many countries and cultures who are referred to the hospital each year. The comprehensive treatment plans are directed toward achieving the best possible long-term outcomes in patients. Shriners has a strong history of conducting excellent research that translates into providing high-quality care to improve physical, functional, and psychological outcomes after burn injury.

Within the Shriners Burn Hospital and University of Texas Medical Branch (UTMB), the Pediatric Burn Injury Rehabilitation Model System contributes to the overall research of the BMS program. In addition to the current longitudinal assessments, UTMB/Shriners BMS Center has a study aimed to improve rehabilitative outcomes for children with burns of 30% or more TBSA burned. The treatment combines an anabolic agent (oxandrolone or ketoconazole or propranolol) with a 3-month intensive outpatient rehabilitation program. The supervised exercise program has shown to be effective in ameliorating effects of the hypermetabolic response. The BMS center also has a project that focuses on acute stress disorder and posttraumatic stress disorder—a problem that impairs the well-being of burn patients. The study follows children with acute stress disorder to assess the relationship of the disorders and to elucidate a history of the development of posttraumatic stress disorder.

Project Director:

David Herndon, MD

Project Coordinator:

Kathy Epperson, RN, BS

Northwest Regional Burn Model System (NWRBMS)

The NWRBMS is centered in the University of Washington Medicine/Surgery area at Harborview Medical Center. NWRBMS's primary activities include conducting research studies on high-priority topics for people with a burn injury. These topics include patients' employment, rehabilitation, depression, and postburn itching. NWRBMS also provides research-based education and training to professionals and consumers.

In addition to contributing to the national database, the NWRBMS is establishing a web-based dissemination platform to provide education on the challenges and processes encountered after a significant burn injury. The target audiences for this collaborative dissemination project include burn survivors, families, employers, medical professionals, case managers, third-party payers, and agencies involved with worker's compensation and vocational rehabilitation. The NWRBMS is also conducting a prospective randomized trial aimed at reducing pain and itch by using hypnosis.

Project Director:

Nicole Gibran, MD

Project Coordinator:

Gretchen Carrougher, RN, MN

Burn Model System National Data and Statistical Center (BMS NDSC)

The BMS NDSC advances medical rehabilitation by increasing the rigor and efficiency of scientific efforts to assess the experiences and outcomes of individuals who have burn injury.

Specifically, the BMS NDSC (1) maintains the national BMS database for data submitted by each [BMS center](#); (2) facilitates the entry of high-quality, reliable data in the BMS database by providing training and technical assistance to BMS centers; (3) facilitates the entry of high-quality data collected from database participants of all racial and ethnic backgrounds by providing knowledge, training, and technical assistance to the BMS centers on culturally appropriate methods of longitudinal data collection and participant retention; (4) supports rigorous research conducted by BMS centers and investigators from outside of the BMS network who are analyzing data from the BMS database by making statistical and other methodological consultation available; (5) improves the efficiency of the BMS database operations through collaboration with other entities, such as the [National Data and Statistical Center for Traumatic Brain Injury Model Systems](#), the [National Data and Statistical Center for Spinal Cord Injury Model Systems](#), the [Model Systems Knowledge Translation Center](#), and the [American Burn Association](#); and (6) provides reports for the public from the BMS database.

Project Director:

Dagmar Amtmann, PhD

Project Coordinator:

Kara McMullen, MPH

Summary of Burn Model System Findings 1994–2016

- 5,936 people consented to participate in the BMS database.
- 477 people died before hospital discharge.
- 849 people did not agree to participate in the study.
- 71% of the participants in the database were male.
- 37% of the participants were younger than 18 years of age at the time of their burn injury.
- 74% of the participants were Caucasian; 19% were African-American; and 29% identified as Hispanic.¹
- Mean TBSA burned was 24% across all participants; mean TBSA grafted was 15%.
- 45% of participants had at least 20% TBSA burned.
- Length of acute care hospital stay averaged 30 days for participants younger than 18 years of age.
- Length of stay averaged 29 days for adults ages 18–30 years, 27 days for adults ages 31–45 years; 30 days for adults ages 46–64 years; 26 days for adults ages 65–74 years; and 28 days for adults ages 75 years and older.
- From 1994 to 2015, 602 participants went on to inpatient rehabilitation after they were discharged from an acute care unit; average inpatient rehabilitation length of stay for those participants was 24 days (the Pediatric Burn Injury Rehabilitation Model System in Galveston does not have an inpatient rehabilitation unit; therefore these numbers reflect patients from three centers).
- In a study completed in 2007, the participants in the BMS database were found to be representative of the larger National Burn Repository database. The study revealed both internal and external validity for this comparison.² The BMS plans to assess representativeness in another study in 2017.

Cause of Injury³

- Fire/flare: 60%
- Scald: 16%
- Grease: 8%
- Electrical: 6%
- Contact with hot object: 4%
- Flash: 3%
- Chemical: 2%

¹ In 2015 the method of collecting race and ethnicity was changed to more closely correspond to U.S. Census data collection.

² Lezotte, D. C., Hills, R. A., Heltshe, S. L., Holavanahalli, R. K., Fauerbach, J. A., Blakeney, P., . . . Engrav, L. H. (2007, December). Assets and liabilities of the Burn Model System data model: A comparison with the National Burn Registry. *Archives of Physical and Medical Rehabilitation*, 88 (12 Suppl. 2), S7–S17.

³ Percentages reported reflect those participants in the database with a known etiology (unknown cause of injury was excluded from this summary). Two percent of participants had “unknown” etiology ($n = 120$).

Demographics

Age Groups and Gender

Figure 1 and Table 1 show the number of burn survivors in the BMS database by age group. Males outnumber females in all categories. People younger than 20 years of age make up 39% of all participants. The percentage of burn survivors is greatest among 20- to 60-year-olds, accounting for 52% of all participants. Table 2 shows the breakdown of gender in the total sample.

Figure 1. Number of Participants by Gender and Age Group

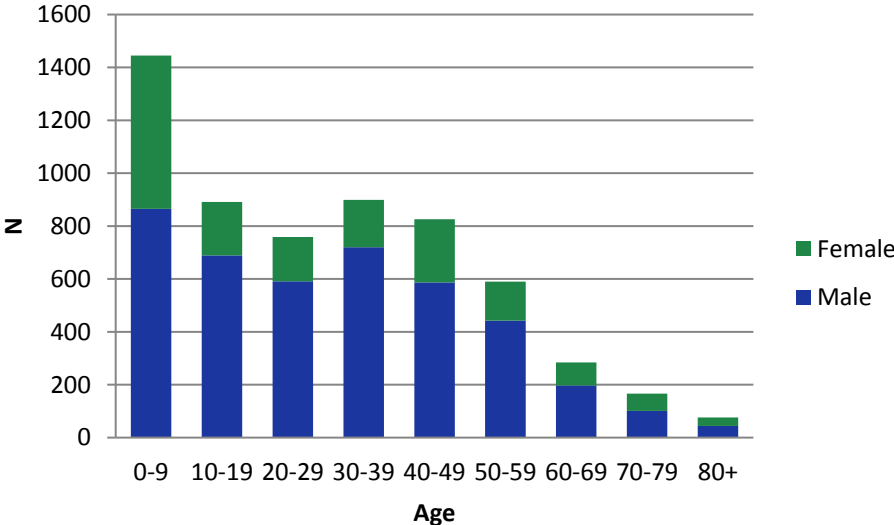


Table 1. Number and Percentage of Participants by Age Group

Age (Years)	Number of Participants	%
0-9	1445	24.3
10-19	891	15.0
20-29	759	12.8
30-39	899	15.1
40-49	826	13.9
50-59	590	9.9
60-69	284	4.8
70-79	166	2.8
80+	76	1.3

Table 2. Number and Percentage of Participants by Gender

Gender	Number of Participants	%
Male	4,236	71.4
Female	1,700	28.6

Race and Ethnicity

Beginning in 2015, the BMS started collecting data on race and ethnicity in a way that more closely resembles the way in which the U.S. Census Bureau collects such data. The BMS now collects data on race and ethnicity separately. Figure 2 and Table 3 show the percentage and number of burn survivors in the BMS database by race and ethnicity. Some data are missing or unknown due to the change in how data are collected. Table 3 shows that 5.8% of records did not specify ethnicity. Figure 2 is based on the records in which race was specified.

Figure 2. Distribution of Participants by Race

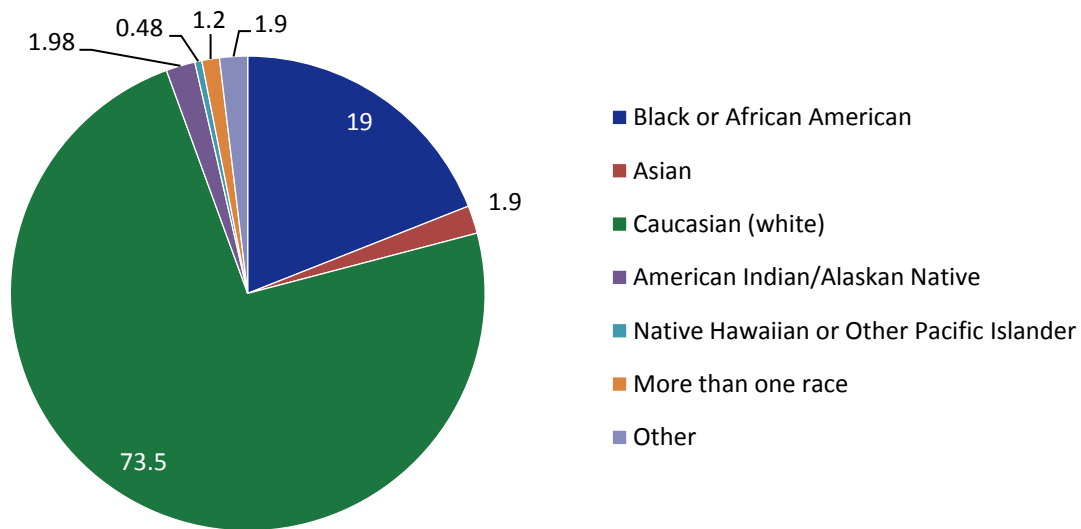


Table 3. Number and Percentage of Participants by Ethnicity

Ethnicity	Number of Participants	%
Hispanic or Latino	1,606	27.1%
Not Hispanic or Latino	4,007	67.5%
Missing/unknown	323	5.4%

Residence and Geographical Location at Time of Injury

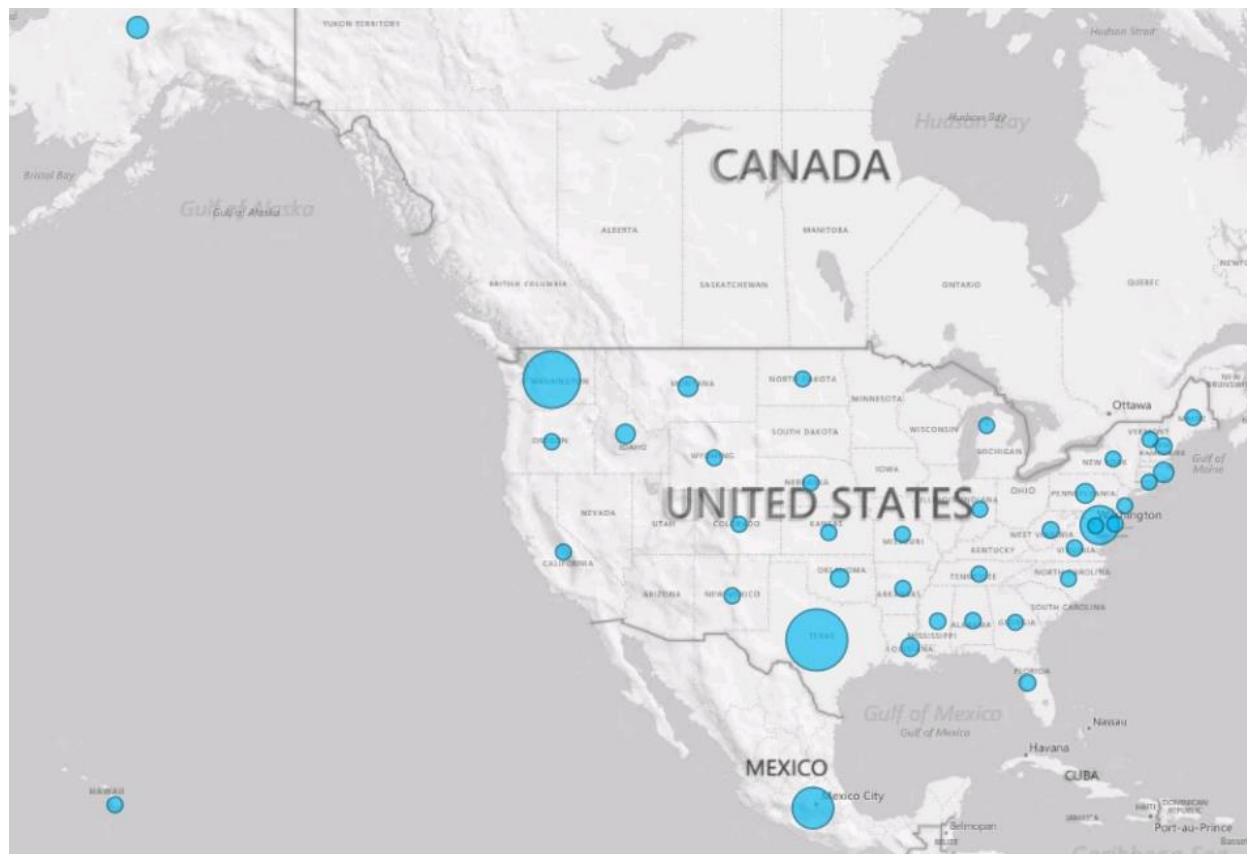
Table 4 shows the number and percentage of participants in the BMS database by type of residence in which they were living at the time of their injury. More than 5% of participants had missing or unknown data.

Figure 3 is a map of the geographic location of burn participants at the time of their injury. Areas with higher concentrations of BMS participants are represented by larger circles.

Table 4. Type of Residence at the Time of Burn Injury

Type of Residence	Number of Participants	%
House	4,009	67.5%
Apartment	1,013	17.1%
Mobile home	383	6.5%
Other	109	1.8%
Homeless	57	1.0%
Institution	24	0.4%
Missing/unknown	341	5.7%

Figure 3. Geographical Location of Residence at Time of Burn Injury



Living Situation at Time of Injury

Figures 4 and 5 depict the living situations of burn survivors—adults and children, respectively—in the BMS database at the time of their injury. At the time of their injuries, the majority of adults lived with a spouse, partner, or significant other, whereas the majority of children lived with both parents.

Figure 4. Distribution of Adults Living With Another Person at the Time of Their Injury

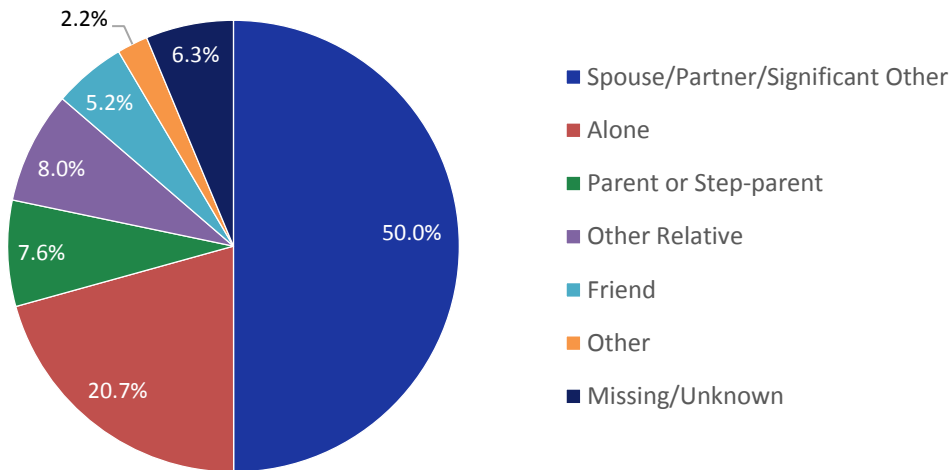
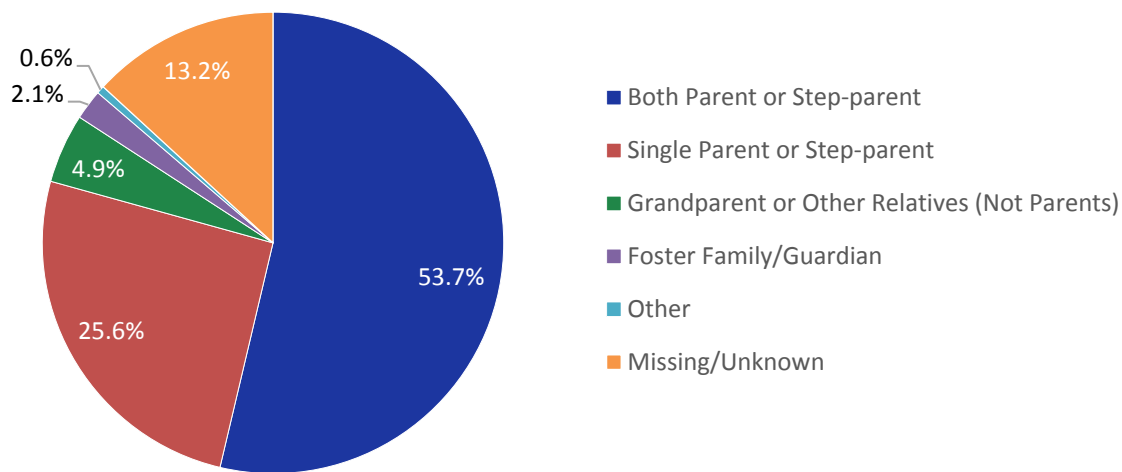


Figure 5. Distribution of Children Living With Another Person at the Time of Their Injury



Employment and School Status at Time of Injury

Table 5 shows the employment status of BMS participants, 18 years of age and older, at the time of their burn injury. Over 2% of participants had missing or unknown data. The majority of adults were employed at the time of their injury. Table 6 shows the school status of children, 5–17 years of age, at the time of their burn injury ($n = 1,197$). The majority of children in this age group were enrolled in school at the time of their injury.

Table 5. Employment Status of Participants, 18 Years of Age and Older, at the Time of Their Injury

Employment Status	Number of Participants	%
Employed	2,326	61.9%
Not employed	923	24.6%
Retired	371	9.9%
Homemaker/caregiver	45	1.2%
Volunteer	7	0.2%
Missing/unknown	85	2.3%

Table 6. School Status of Participants, 5–17 Years of Age, at the Time of Their Injury

School Status	Number of Participants	%
In school	963	82.0%
Not in school	166	14.1%
Missing/unknown	46	3.9%

Adults Reporting Pre-Injury Alcohol Use and Drug Use

Table 7 lists pre-injury alcohol and drug use for adults as measured by the CAGE. The CAGE is a commonly used assessment for alcohol problems. The name comes from an acronym of the four questions in the measure. The amount of missing data varies for each of these variables but is approximately 8% for each.

Table 7. Pre-Injury Alcohol and Drug Use

Pre-Injury Alcohol and Drug Use	Number of Participants	%
Alcohol use indicating a potential problem in past 12 months	539	13.0
Drug use indicating a potential problem in past 12 months	408	10.9

Participants Reporting Pre-Existing Physical Disability

Table 8 identifies the prevalence of physical disability before the burn injury among participants in the BMS database. Data for this type of information are missing for 7.8% of the records.

Table 8. Pre-Injury Disability

Disability	Number of Participants	%
Pre-injury physical disability	465	7.8

Participants Reporting Psychiatric Treatment in the Year Prior to the Injury

Table 9 identifies the prevalence of psychiatric treatment before the burn injury among participants in the BMS database. Data for this type of information are missing for 13.9% of the records.

Table 9. Pre-Injury Psychiatric Treatment

Psychiatric Treatment	Number of Participants	%
Psychiatric treatment in past 12 months	481	8.1

Characteristics of Burn Injury

Total Body Surface Area Burned

Figure 6 shows the number of participants in the BMS database by burn size. Among database records that reported burn size, 51% of participants had less than 20% TBSA burned. Only 7.8% of participants had burns on 60% or more TBSA.

Table 10 shows the percentage of participants in each category of total burn size. Very few (0.6%) participants had burn size that was unknown or not recorded.

Figure 6. Number of Participants by Burn Size Category (% TBSA Burned)

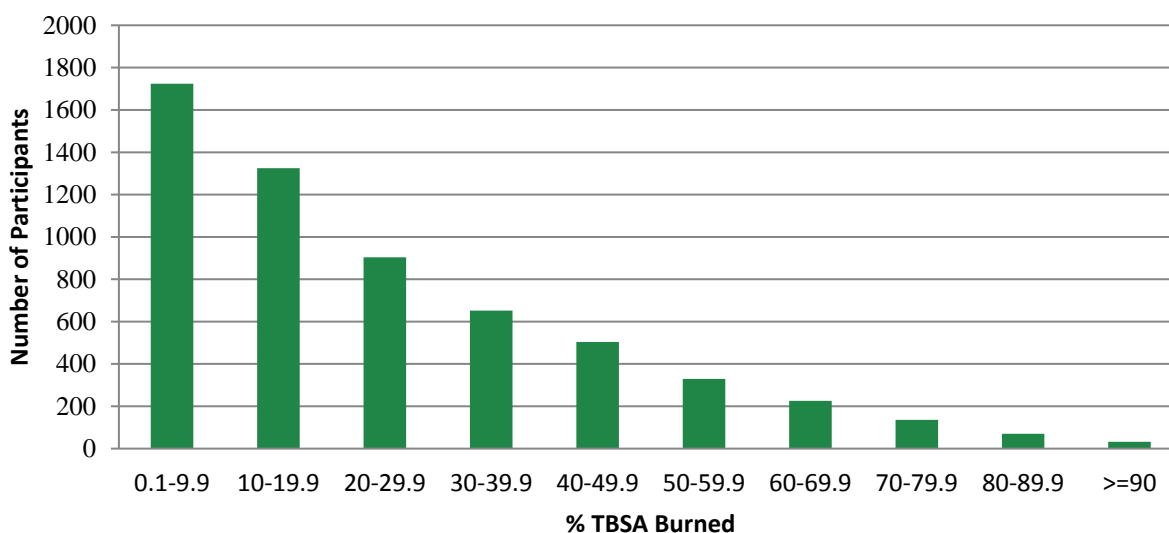


Table 10. Number and Percentage of Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Number of Participants	%
0.1-9.9	1,724	29.2%
10-19.9	1,325	22.5%
20-29.9	904	15.3%
30-39.9	652	11.0%
40-49.9	504	8.5%
50-59.9	329	5.6%
60-69.9	226	3.8%
70-79.9	136	2.3%
80-89.9	70	1.2%
≥90	32	0.5%
Missing/unknown	34	0.57%
Total	5,936	

Burn Location on the Body

Table 11 presents data on the bodily location of burn injuries for participants in the BMS database.

Table 11. Burn Injury Location

Location	Yes	%	Missing/Unknown	%
Head/neck burn	3,299	55.6%	71	1.2%
Trunk burn	3,734	62.9%	60	1.0%
Perineum burn*	911	15.3%	542	9.1%
Arm burn (right, left, or bilateral)	4,170	70.2%	55	0.9%
Hand burn (right, left, or bilateral)	3,897	65.7%	73	1.2%
Leg burn (right, left, or bilateral)	3,509	59.1%	61	1.0%
Foot burn (right, left, or bilateral)	1,872	31.5%	88	1.5%

*The variable assessing perineum burn was added to data collection later than the other body locations listed in this table.

Total Body Surface Area Grafted

Data on graft size among participants in the BMS database were unknown or not recorded for 7.7% of the records. Among participants with available data, about 72% had a TBSA graft size of 19.9% or smaller, and only 8.1% had a TBSA graft size of 50% or more.

Table 12 shows the number and percentage of patients in each category of percent TBSA grafted.

Table 12. Number and Percentage of Participants by Percent TBSA Grafted

% TBSA Grafted	Number of Participants	%
0–9.9	3,056	51.5%
10–19.9	865	14.6%
20–29.9	513	8.6%
30–39.9	326	5.5%
40–49.9	272	4.6%
50–59.9	190	3.2%
60–69.9	107	1.8%
70–79.9	84	1.4%
80–89.9	49	0.8%
≥90	16	0.3%
Missing/unknown	458	7.7%
Total	5,936	

Graft Location

Table 13 presents data on the bodily location of burn grafts among participants in the BMS database.

Table 13. Burn Graft Location

Location	Yes	%	Missing/Unknown	%
Head/neck graft	1,124	18.9%	160	2.7%
Trunk graft	2,270	38.2%	147	2.5%
Perineum graft*	420	7.1%	747	12.6%
Arm graft (right, left, or bilateral)	2,990	50.4%	135	2.3%
Hand graft (right, left, or bilateral)	2,512	42.3%	164	2.8%
Leg graft (right, left, or bilateral)	2,587	43.6%	142	2.4%
Foot graft (right, left, or bilateral)	1,300	21.9%	175	2.9%

*The variable assessing perineum burn was added to data collection later than the other body locations listed in this table.

Cause of Injury

Figure 7 shows the distribution of causes of injury among participants in the BMS database. Data on cause of injury among participants were unknown or not recorded for 2.0% of the records in the database. Among participants with available data, over 59% were injured by fire/flame. Table 14 presents data on the number and percentage of participants in each injury category. The "Other" burn category includes abrasions, hydrofluoric acid, frostbite, skin disease, and other causes. The BMS inclusion criteria have changed since the beginning of the program; frostbite and skin disease are no longer eligible causes of burn injury.

Figure 8 shows the number of burn injuries among participants by cause of injury and age group. As seen in this figure, different burn injuries are more prevalent for certain age groups.

Figure 7. Distribution of Participants by Cause of Injury

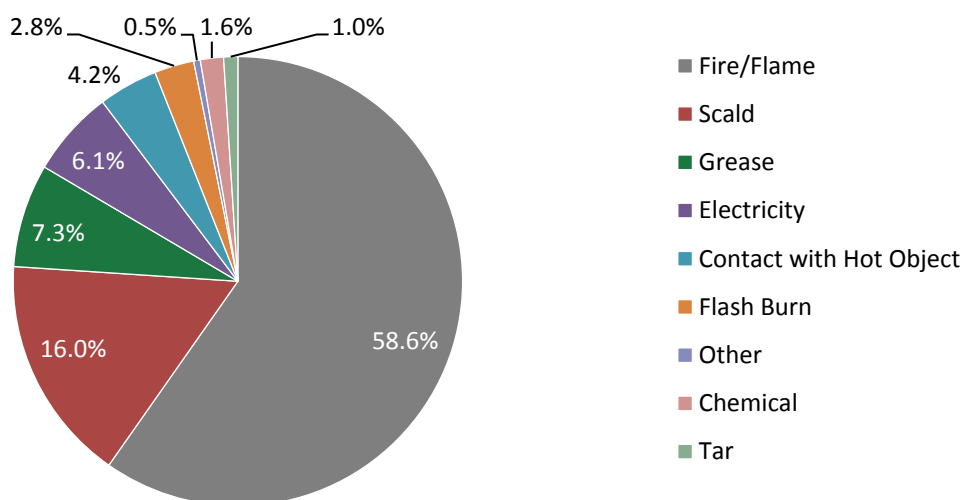
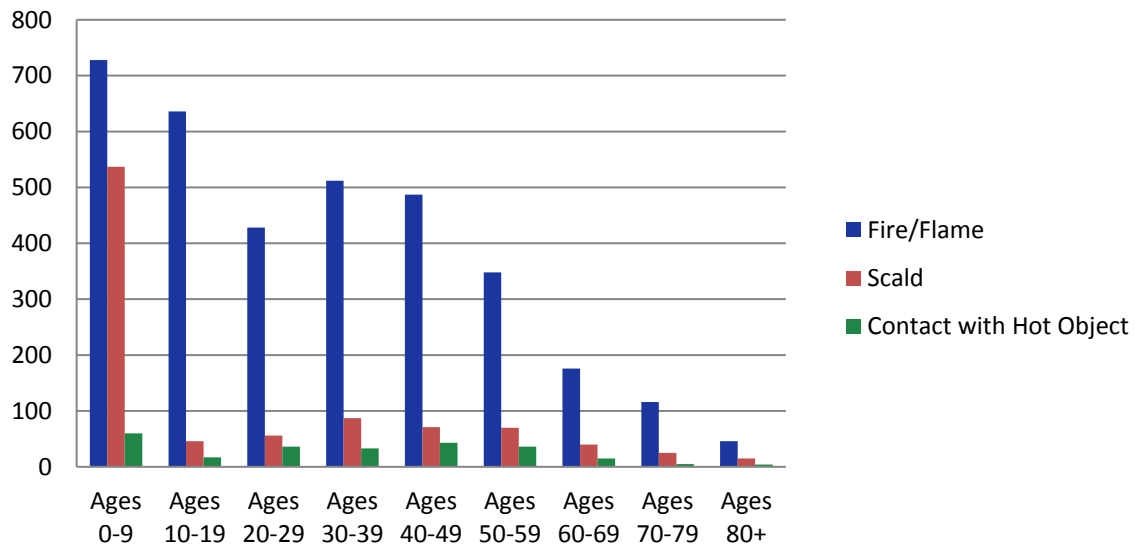


Table 14. Number and Percentage of Participants by Cause of Injury

Cause of Injury	Number of Participants	%
Fire/Flame	3477	58.6%
Scald	947	16.0%
Grease	434	7.3%
Electricity	362	6.1%
Contact with Hot Object	249	4.2%
Flash Burn	167	2.8%
Other	27	0.5%
Chemical	95	1.6%
Tar	58	1.0%
Unknown/Missing	120	2.0%

Figure 8. Number of Participants by Cause of Injury and Age Group



Circumstances and Place of Injury

Table 15 and Figure 9 provide data on the circumstances of injury among participants in the BMS database. Data on the circumstances of injury were unknown for 1.9% of participants. Figure 9 is based on participants whose circumstances of injury were known. The majority of burn injuries in the database were considered nonintentional, 16% of which were related to employment. About 6% of burn injuries were considered intentional.

Table 16 identifies the place (closed/indoors versus open/outdoors) in which the injury occurred among participants in the BMS database. The majority of injuries occurred indoors. Figure 10 identifies the location at which the injury occurred by percent TBSA burned (based on available data).

Table 15. Number and Percentage of Participants by Circumstance of Injury

Circumstance of Injury	Number of Participants	%
Non-intentional non-work related	3025	51.0%
Non-intentional employment related	945	15.9%
Non-intentional recreation	764	12.9%
Non-intentional unspecified	708	11.9%
Suspected assault--domestic	132	2.2%
Suspected self-inflicted/suicide	130	2.2%
Suspected assault--non-domestic	78	1.3%
Suspected arson	21	0.4%
Skin disease	23	0.4%
Missing/unknown	110	1.9%

*The BMS inclusion criteria no longer include this circumstance; this change was made in 2010.

Figure 9. Distribution of Participants by Circumstance of Injury

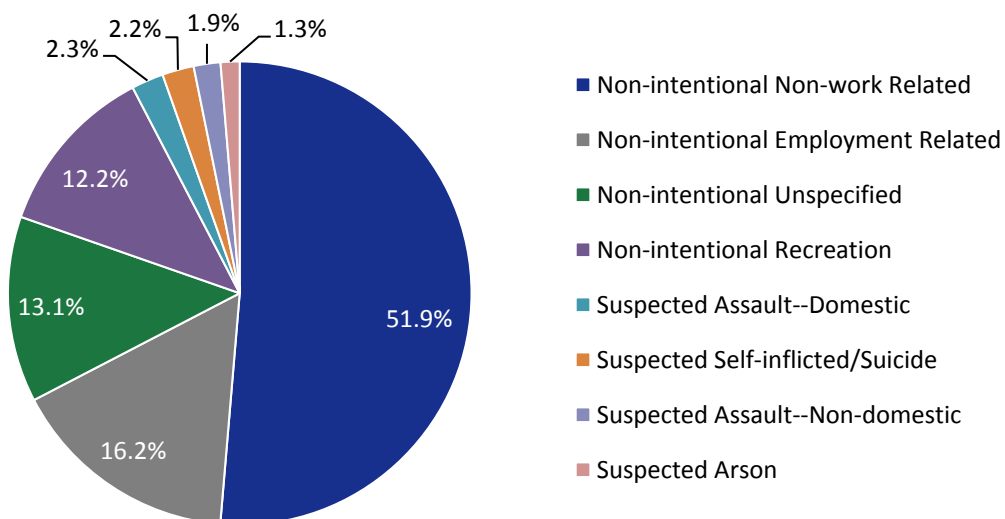
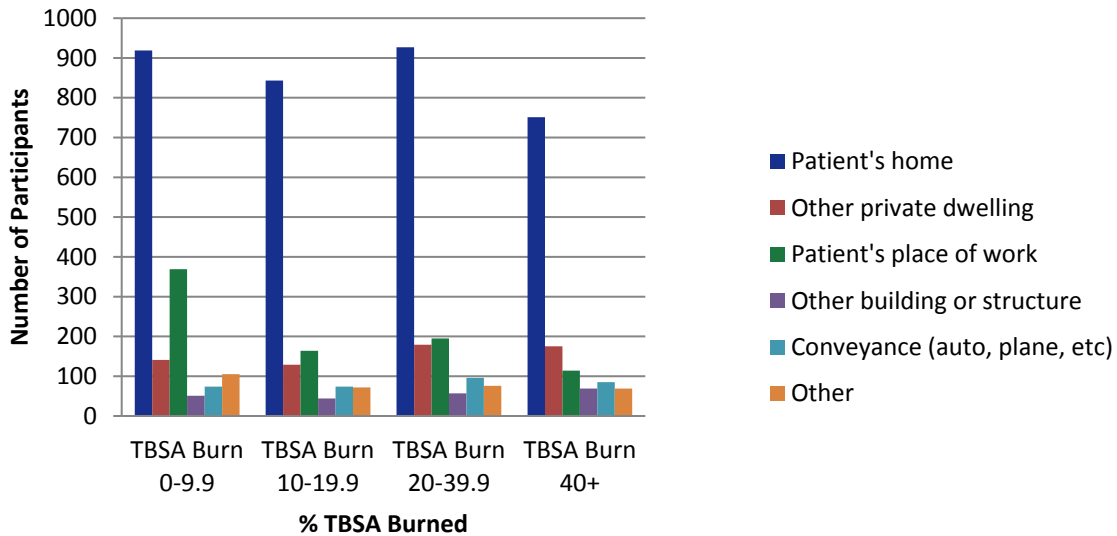


Table 16. Number and Percentage of Participants by Place of Injury

Place of Injury	Number of Participants	%
Closed/Indoors	3463	60.2%
Open/outdoors	2296	39.9%
Missing/unknown	177	3.1%

Figure 10. Location of Injury Among Participants by Burn Size Category (% TBSA Burned)



Inhalation and Other Injuries

Table 17 identifies the incidence of inhalation injuries and other injuries among participants in the BMS database. Table 18 provides data on these injuries by gender (based on available data).

Table 17. Number and Percentage of Participants by Inhalation and Other Types of Injuries

Type of Injury	Number of Participants	%
Inhalation injury	906	15.6
Other injury	730	12.6
Range of motion deficit	2,800	52.9

Table 18. Percentage of Participants With Inhalation and Other Injuries by Gender

Gender	Inhalation Injury %	Other Injuries%
Males	14.9	13.0
Females	17.3	11.8

Treatment Before Discharge

Length of Acute Care Hospital Stay

Figure 11 shows the average length of acute care hospital stay per year among participants in the BMS database. Only 17 records (0.3%) in the database were missing data on the length of hospital stay. Figure 11 is based on available data. From 1993 to 2016, the average length of stay was 29 days. Length of stay varies across years, with no downward or upward trend. Table 19 shows the average length of hospital stay by percent TBSA burned.

Figure 11. Average Length of Acute Care Hospital Stay Among Participants by Year (1993–2016)

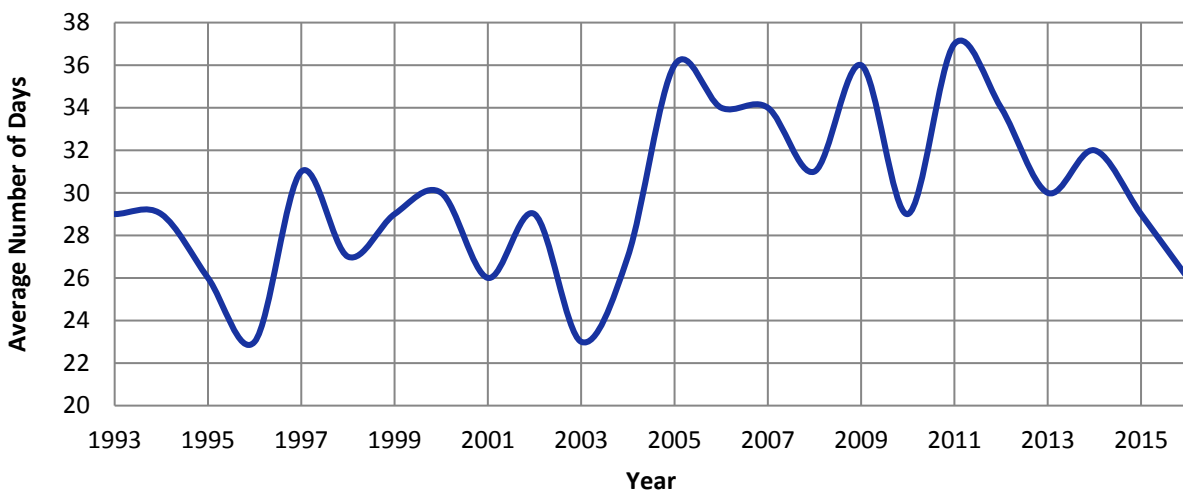


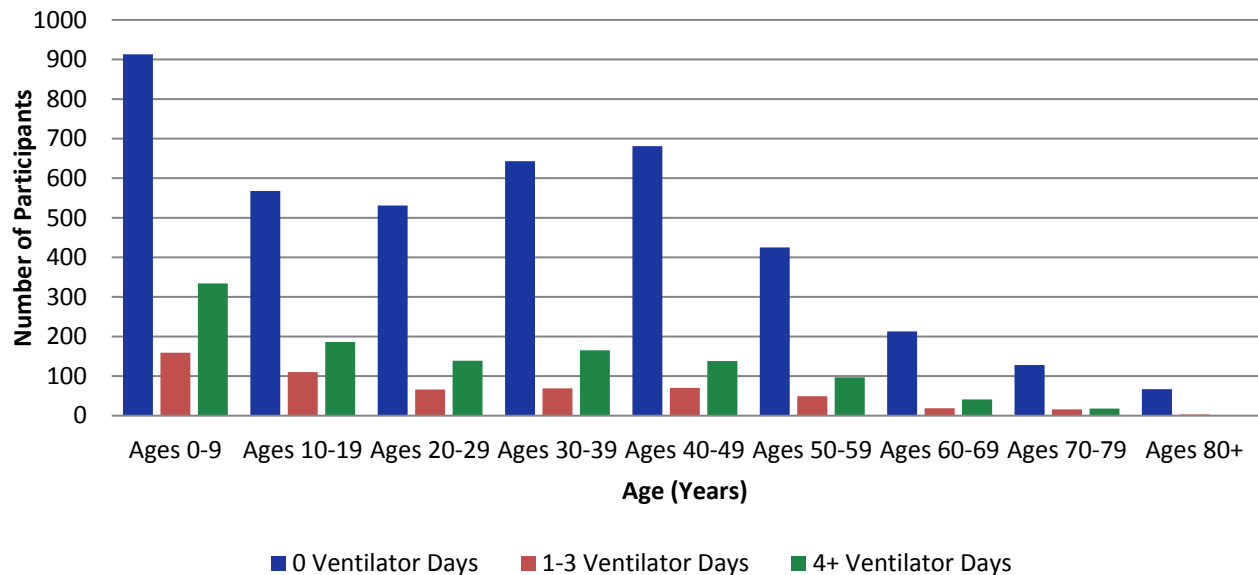
Table 19. Average Length of Acute Care Hospital Stay Among Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Average Length of Hospital Stay (Days)
0–9.9	16.2
10–19.9	20.2
20–29.9	27.7
30–39.9	34.2
40–49.9	41.9
50–59.9	47.2
60–69.9	55.8
70–79.9	68.6
80–89.9	80.8
≥90	178.1

Ventilator Days

Figure 12 presents data on the number of days on which participants in the BMS database spent on a ventilator for different age groups. Data for this variable were unknown or missing for 5% of the records in the database. Figure 12 is based on available data. The mean number of days on the ventilator was 4 days for the entire sample; the mean number of days for only those who had spent any time on a ventilator was 13 days.

Figure 12. Number of Participants and Days on Which They Spent on a Ventilator by Age Group



Inpatient Rehabilitation Days

Table 20 presents the number of rehabilitation days among participants in the BMS database. The majority of participants did not go to inpatient rehabilitation upon discharge from the hospital.

Table 20. Number and Percentage of Participants Who Went to Inpatient Rehabilitation by Number of Days in Inpatient Rehabilitation

Inpatient Rehabilitation Days*	Number of Participants	%
Did not go to rehab (0 inpatient rehab days)	3,551	75.8%
1–10 days of rehab	158	3.4%
11–20 days of rehab	207	4.4%
≥21 days of rehab	236	5.0%
Missing/unknown	531	11.3%

*Does not include data from the Pediatric Burn Injury Rehabilitation Center at UTMB, which does not have an inpatient rehabilitation center.

Hospital Discharge Data

Hospital Disposition

Figure 13 shows the distribution of participants in the BMS database by type of disposition at hospital discharge. Figure 13 is based on available data. Table 21 identifies the number and percentage of each type of disposition for the sample.

Figure 13. Distribution of Participants by Type of Disposition at Hospital Discharge

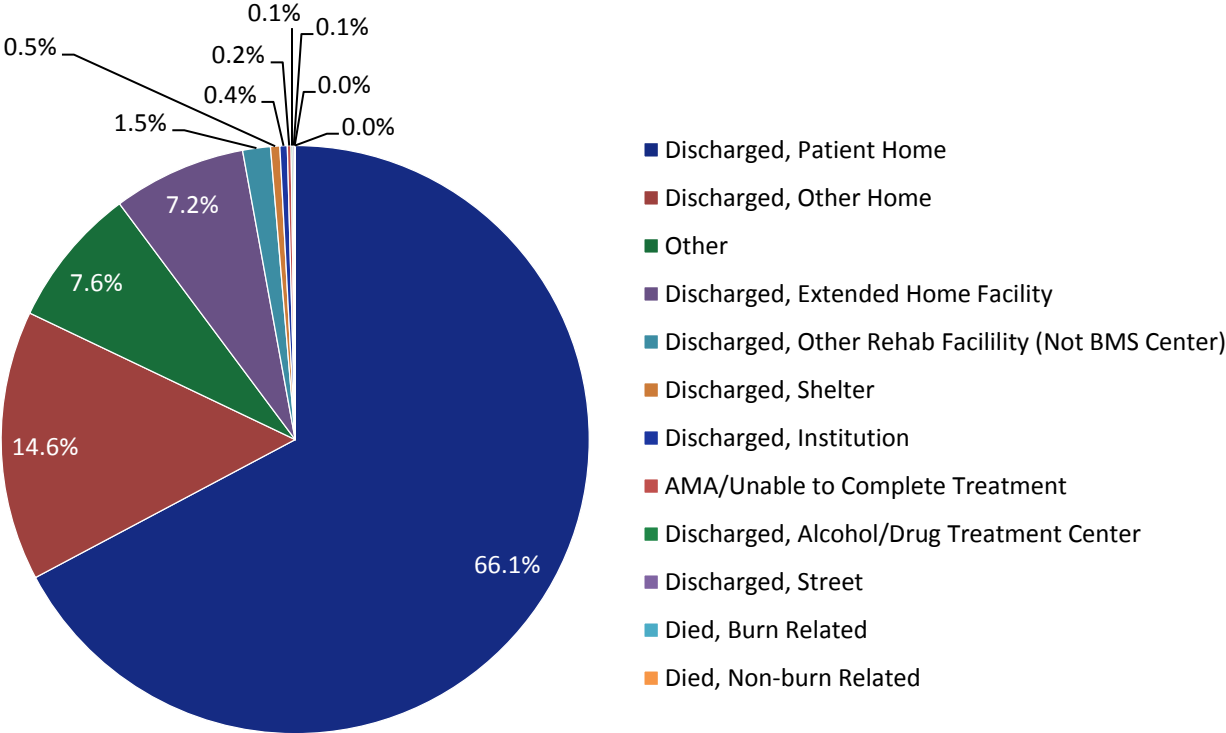


Table 21. Number and Percentage of Participants by Type of Disposition at Hospital Discharge

Disposition	Number of Participants	%
Discharged, patient home	3,921	66.1%
Discharged, other home	869	14.6%
Other	450	7.6%
Discharged, extended home facility	428	7.2%
Discharged, other rehab facility (not BMS Center)	89	1.5%
Discharged, shelter	27	0.5%
Discharged, institution	26	0.4%
Unable to complete treatment	14	0.2%
Discharged, alcohol/drug treatment center	4	0.1%
Discharged, street	5	0.1%
Died, burn related	1	0.0%
Died, not burn related	1	0.0%
Missing/unknown	101	1.7%

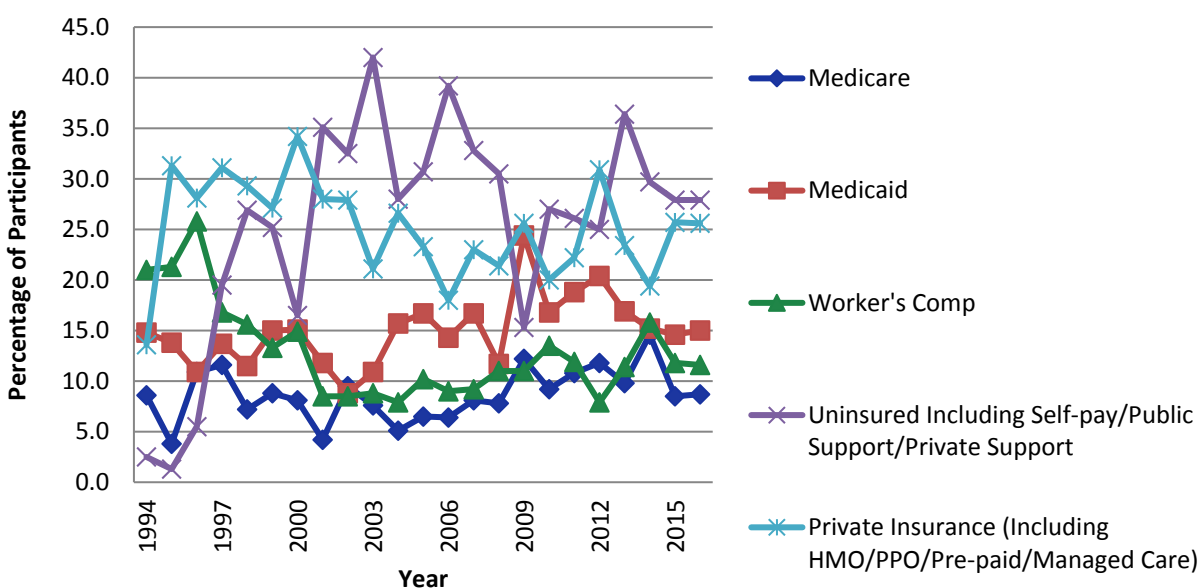
Primary Sponsor of Care at Discharge

Table 22 identifies the primary sponsor of hospital care among participants in the BMS database at the time of hospital discharge. Data for this variable were unknown or missing for over 11% of the records in the database. Figure 14 identifies selected types of insurance (e.g., Medicare, Medicaid, private insurance, and no insurance) among participants by year. The types of insurance varied among participants. Figure 14 is based on available data.

Table 22. Number and Percentage of Participants by Primary Sponsor of Care at Discharge

Primary Sponsor of Care at Discharge	Number of Participants	%
Philanthropy or private support	1,003	16.9%
Private insurance	852	14.4%
Medicaid	790	13.3%
Worker's compensation/labor and industries	613	10.3%
Other	531	8.9%
Health Maintenance Organization (HMO)/Preferred Provider Organization (PPO)/prepaid/managed care	497	8.4%
Medicare	459	7.7%
Self-pay	335	5.6%
Indigent or public support	133	2.2%
Champus	28	0.5%
Veterans Affairs	22	0.4%
Missing/unknown	673	11.3%

Figure 14. Percentage of Participants With Selected Types of Insurance by Year



Treatment After Discharge

Burn-Related Surgeries and Therapy Use

Table 23 identifies the types of post-discharge surgeries among participants in the BMS database. Table 24 lists the types of therapy (e.g., physical [PT], occupational [OT], and psychological/peer support therapy) at each follow-up. These variables have only been collected since 2009; therefore this data applies to only those participants injured since 2009 ($n = 1,476$). Percentages reflect only available data. Figure 15 displays the distribution of types of surgery across all follow-ups combined.

Table 23. Number and Percentage of Participants by Type of Surgery Since Last Follow-Up

Type of Surgery Since Last Follow-Up*	6 Months		12 Months		24 Months	
	Number of Participants	%	Number of Participants	%	Number of Participants	%
Burn-related surgeries since last follow-up	233	17	274	21.7	276	24.7
Surgery for open wounds**	74		54		43	
Surgery for joint contractures**	115		149		144	
Surgery for scar management**	125		163		187	

*Data collection for these variables began in 2009.

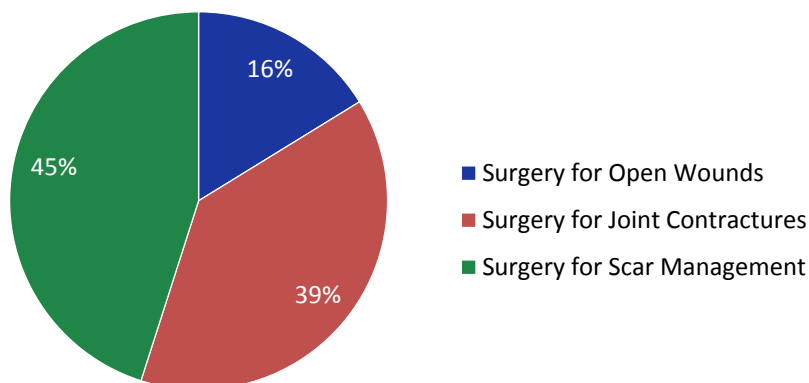
**A given participant may have had more than one type of surgery and more than one occurrence of any given type of surgery.

Table 24. Number and Percentage of Participants by Therapy Use Since Last Follow-Up

Therapy Use Since Last Follow-Up*	6 Months		12 Months		24 Months	
	Number of Participants	%	Number of Participants	%	Number of Participants	%
OT/PT	722	54	518	41.4	324	29.1
Psychological or peer support therapy	289	23	233	18.9	205	18.6

*Data collection for these variables began in 2009.

Figure 15. Distribution of Types of Surgery Among Participants at All Follow-Ups Combined



Physical Outcomes After Burn Injury

Physical Issues in Adults

Table 25 presents data on various physical issues among adults in the BMS database at three time-points. Data on these variables have only been collected since 2015; therefore this data applies to only those participants injured since 2015 (*n* = 258). Percentages reflect participants for whom there is data for these physical issues.

Table 25. Physical Issues in Adults

Physical Issues*	6 Months		12 Months		24 Months		5 years	
	N	%	N	%	N	%	N	%
Hearing loss	20	13.5%	17	14.9%	17	15.2%	1	2.6%
Change in voice	14	9.5%	8	7.0%	15	13.4%	6	15.8%
Vision problems not corrected by contacts or glasses	20	13.5%	18	15.8%	9	8.0%	7	18.4%
Eyelid problems	6	4.1%	1	0.9%	7	6.3%	4	10.5%
Excessive tearing of the eyes	11	7.4%	11	9.6%	3	2.7%	4	10.5%
Difficulty with memory	42	28.4%	31	27.2%	30	26.8%	17	44.7%
Difficulty with thought processing	29	19.6%	21	18.4%	25	22.3%	13	34.2%
Numbness, pins and needles or burning sensations in burn scar	103	69.6%	74	64.9%	54	48.2%	18	47.4%
Numbness, pins and needles or burning sensations in hands	74	50.0%	43	37.7%	41	36.6%	17	44.7%
Numbness, pins and needles or burning sensations in feet	47	31.8%	35	30.7%	30	26.8%	13	34.2%
Trouble with balance	46	31.1%	37	32.5%	29	25.9%	14	36.8%
Varicose veins	9	6.1%	7	6.1%	10	8.9%	1	2.6%
Swollen feet or legs	36	24.3%	27	23.7%	20	17.9%	11	28.9%
Swollen hands or arms	19	12.8%	11	9.6%	10	8.9%	6	15.8%
Difficulty with breathing when doing regular activities	24	16.2%	22	19.3%	13	11.6%	9	23.7%
Skin cancer	2	1.4%	1	0.9%	2	1.8%	2	2.6%

*Data collection for these variables began in 2015.

Physical Issues in Children

Table 26 presents data on various physical issues among children in the BMS database at three time-points. Data on these variables have only been collected since 2015; therefore this data applies to only those participants injured since 2015 (n=138). Percentages reflect participants for whom there is data for these physical issues. Data is collected either by self-report for participants who are ages 13-17, or by proxy for participants who are ages 0-12, using a modified version of the Child Health Conditions Questionnaire (CHC).

Table 26. Physical Issues in Children

Problems with...	6 Months		12 Months		24 Months		5 years	
	N	%	N	%	N	%	N	%
Seeing	6	6.0%	8	8.9%	3	4.1%	11	19.6%
Hearing	2	2.0%	2	2.2%	2	2.7%	3	5.4%
Learning and understanding	7	7.0%	4	4.4%	16	21.9%	10	17.9%
Controlling emotions or behavior	28	28.0%	21	23.3%	33	45.2%	13	23.2%
Sleeping	32	32.0%	13	14.4%	12	16.4%	10	17.9%
Breathing	7	7.0%	6	6.7%	5	6.8%	5	8.9%
Chronic open skin areas	18	18.0%	10	11.1%	8	11.0%	7	12.5%
Other skin problems	8	8.0%	3	3.3%	6	8.2%	5	8.9%
Seeing	6	6.0%	8	8.9%	3	4.1%	11	19.6%
Hearing	2	2.0%	2	2.2%	2	2.7%	3	5.4%
Learning and understanding	7	7.0%	4	4.4%	16	21.9%	10	17.9%
Controlling emotions or behavior	28	28.0%	21	23.3%	33	45.2%	13	23.2%
Sleeping	32	32.0%	13	14.4%	12	16.4%	10	17.9%
Breathing	7	7.0%	6	6.7%	5	6.8%	5	8.9%
Chronic open skin areas	18	18.0%	10	11.1%	8	11.0%	7	12.5%
Other skin problems	8	8.0%	3	3.3%	6	8.2%	5	8.9%

Physical Function, Sleep, and Fatigue among Adults

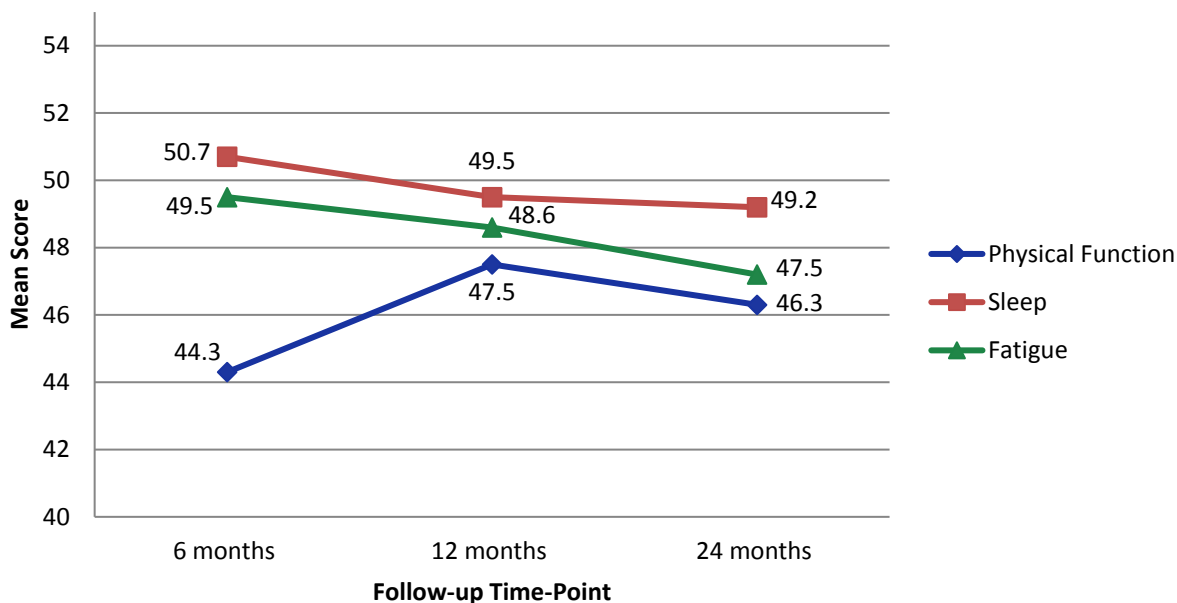
Table 27 presents data on the physical function, sleep, and fatigue scores among adult participants in the BMS database at three time-points. These problems are assessed using the PROMIS 29 scale⁴, which collects data on several areas of functioning and then provides norm scores that can be compared to the general population. The scoring is calculated such that a score of 50 (from a possible range of 0-100) is the general population score. These variables have only been collected since 2015; therefore, these data apply only to those participants injured since 2015 ($n = 258$). Figure 16 shows the trend in mean pain, itch, and sleep problems. Over time, problems with pain or sleep remain relatively constant, while problems with itch trend downward.

Table 27. Mean Physical Function, Sleep, and Fatigue Scores by Time-point for Adult BMS Participants

	6 Months		12 Months		24 Months	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Physical Function	44.3 (9.9)	142	47.5 (10.0)	110	46.3 (10.3)	116
Sleep	50.7 (10.6)	142	49.5 (10.0)	112	49.2 (9.8)	116
Fatigue	49.5 (11.2)	139	48.6 (10.2)	111	47.5 (11.4)	113

*Data collection for these variables began in 2015.

Figure 16. Mean Physical Function, Sleep, and Fatigue Scores by Time-point for Adult BMS Participants



⁴ For more information on PROMIS, see <http://www.healthmeasures.net/explore-measurement-systems/promis>

Functional Outcomes After Burn Injury

Veterans Rand-12/SF-12 Mental and Physical Health Scores

Table 28 presents the mean VR12/SF-12 Mental Health Component (MCS) and Physical Health Component (PCS) scores for adult participants, in the BMS database at each follow-up time-point. The SF12/VR-12 are sets of questions that clinicians ask patients to understand how people are doing physically and mentally. Possible scores range from 0 to 100, with higher scores indicating better health. The average mental and physical health score across the U.S. population is 50.0. The BMS moved from the SF-12 to the VR-12 in 2015. The data presented here presents MCS and PCS scores as collected by both the SF-12 and the VR-12. For comparison purposes, Figure 17 presents the BMS and norm (or general) population scores across time.

Table 28. Mean SF12/VR12 Scores Among Adult BMS Participants

Mean VR-12/SF12* Scores, Adults	Pre-Burn (Administered at Discharge)		Discharge		6 Months		12 Months		24 Months	
	Mean	N	Mean	N	Mean	N	Mean	N	Mean	N
MCS	52.1	2204	46.2	2186	47.6	1553	47.8	1424	48.1	1241
PCS	52.2	2204	31.7	2186	43.6	1553	45.2	1424	46.7	1241

*SF-12v2™ Health Survey © 1994, 2002 by QualityMetric Incorporated and Medical Outcomes Trust. All Rights Reserved. SF-12® is a registered trademark of Medical Outcomes Trust. (SF12v2 Standard, U.S. Version 2.0).

Figure 17a. VR-12/SF12* Mental Health Scores By Time-point Among Adult BMS Participants and Norm Populations

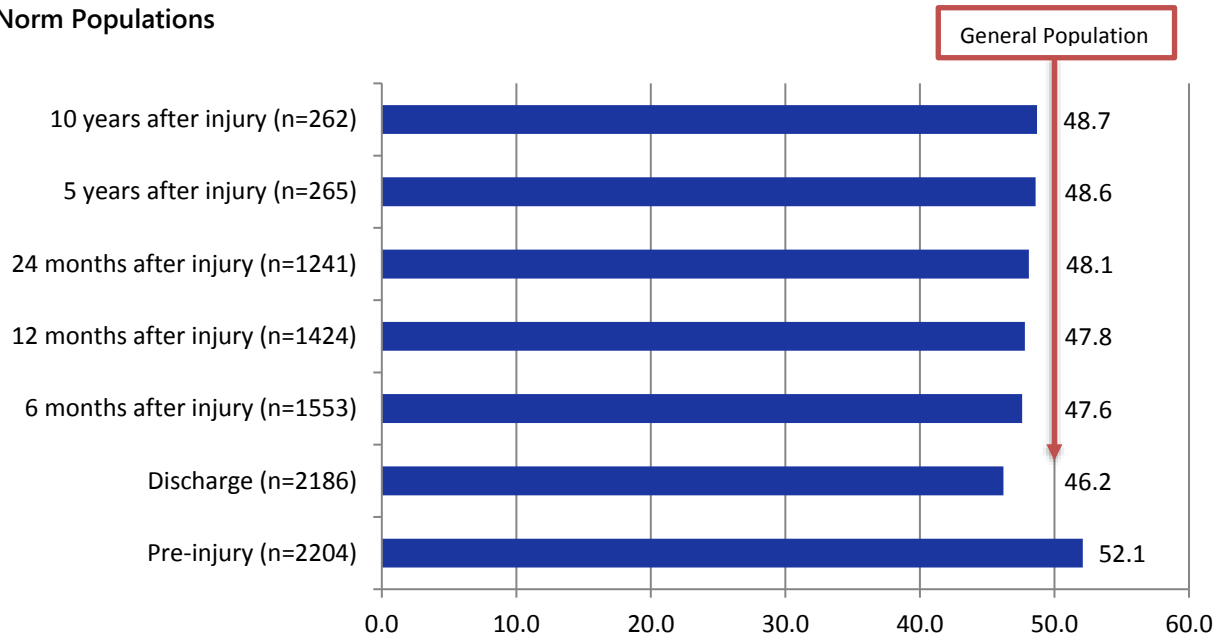
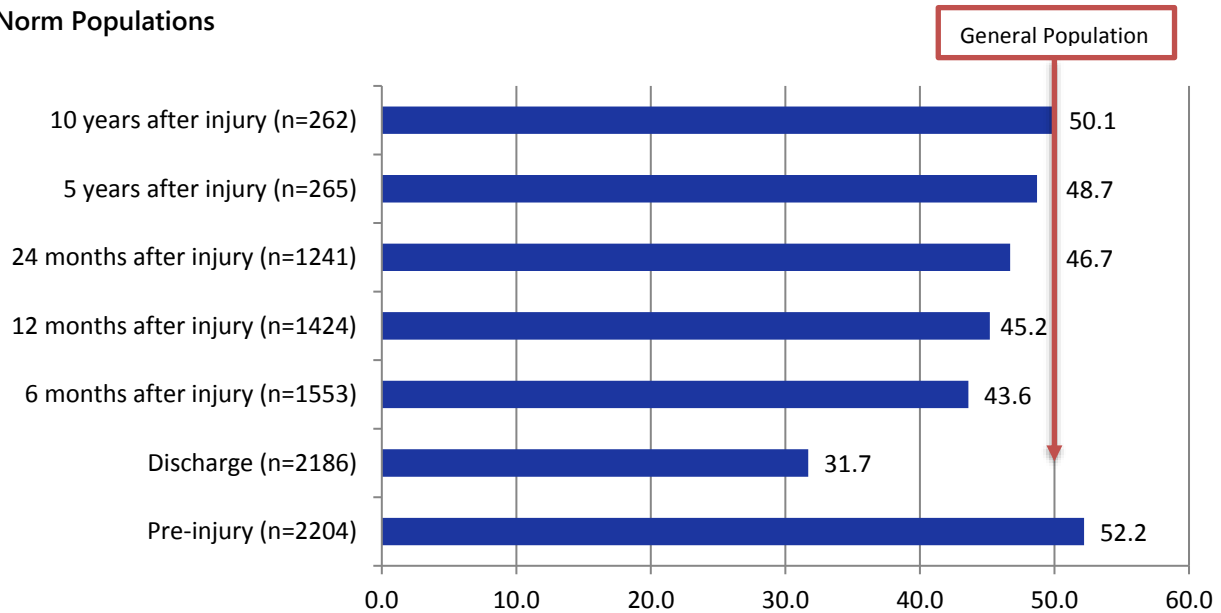


Figure 17b. VR-12/SF12* Physical Health Scores By Time-point Among Adult BMS Participants and Norm Populations



*SF-12v2™ Health Survey © 1994, 2002 by QualityMetric Incorporated and Medical Outcomes Trust. All Rights Reserved. SF-12® is a registered trademark of Medical Outcomes Trust (SF12v2 Standard, U.S. Version 2.0).

**Administered at discharge.

***Norm population is based on a general population score used specifically for comparing data to a “normal population” in this measure.

Social Outcomes After Burn Injury

Employment Status and School Status

Table 29 presents data on the post-burn injury employment status at follow-up of adults, 18 years of age and older, in the BMS database ($n = 3,757$), and is based on only available data. Table 31 presents data on the post-injury school status at follow-up of children, 5–17 years of age, in the BMS database ($n = 1,341$). Like employment status for adults, data on school status among children have not been collected during the entire span of the BMS. Therefore, Table 31 is based on only available data.

Table 29. Employment Status After Burn Injury Among Adult Participants (≥18 Years of Age)

Employment Status*	6 Months		12 Months		24 Months	
	Number of Participants	%	Number of Participants	%	Number of Participants	%
Working	1063	32.0%	1104	37.2%	1015	35.1%
Not Working	1737	52.3%	1359	45.8%	1057	36.5%
Homemaker/Caregiver	27	0.8%	31	1.0%	28	1.0%
Volunteer	15	0.5%	5	0.2%	9	0.3%
Retired	271	8.2%	250	8.4%	611	21.1%
Not applicable	210	6.3%	217	7.3%	175	6.0%

*Data collection for these variables began in 2009.

Table 30. School Status After Burn Injury Among Child Participants (5–17 Years of Age)

School Status*	6 Months		12 Months		24 Months	
	Number of Participants	%	Number of Participants	%	Number of Participants	%
In school	424	81.7%	418	81.0%	395	80.0%
Not school	95	18.3%	98	19.0%	99	20.0%

*Data collection for these variables began in 2009.

New Burn Model System Data Collection

The Burn Model System started collecting data on new variables and measures in 2015, using psychometrically sound, standardized instruments, such as those developed by the PROMIS initiative, which is funded by the National Institutes of Health (NIH). Table 31 describes the instruments and what they measure (i.e., domains) and provides additional information.

Table 31. Summary of New BMS Data Collection Instruments and Measures

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Domain: Demographics (including income, marital status, living situation, work status, school status, etc.)					
Demographics	Discharge and all follow-ups	Some items are new, such as household income. Some have been previously collected, such as living situation and work status.	Proxy (ages 0–17); self-report (ages ≥13)	BMS	25
Domain: Burn Injury Information					
Medical Record Abstraction Form	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	All follow-up points, not pre-burn (administered at discharge) or discharge	Some items are new, such as the ability to drive. Some have been previously collected, such as physical or psychological therapy.	Proxy (ages 0–17); self-report (ages ≥13)	BMS	15

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Domain: Medical Conditions					
Review of Systems	Pre-burn (administered at discharge), discharge, and all follow-ups	New	Ages ≥18	BMS	52
Child Health Conditions	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 0–17); self-report (ages 13–17)	Standardized	19
Domain: Health Related Quality of Life					
Veteran's Rand 12	Pre-burn (administered at discharge), discharge, and all follow-ups	New (replaces the SF12)	Ages ≥18	Standardized	12
Domain: Global Health (including depression, fatigue, anxiety, peer relationships, anger)					
PROMIS 29	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Ages ≥18	Standardized	29
PROMIS 25	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Self-report (ages 8–17)	Standardized	25
Domain: Community Participation					
Community Integration Questionnaire	Pre-burn (administered at discharge) and all follow-ups	Previously administered	Ages ≥14	Standardized	6

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
PROMIS Peer Relationships	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	7
Domain: Depression					
Suicide Item From Patient Health Questionnaire-9	Pre-burn (administered at discharge), discharge, and all follow-ups	New	Ages ≥18	Standardized	1
PROMIS Sadness	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	4
PROMIS Depressive Symptoms	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	6
NIH Toolbox Sadness	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 3–7)	Standardized	4
Domain: Anger					
PROMIS Anger	All follow-ups, pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	6
NIH TB Anger	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 3–7)	Standardized	4

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Domain: Stigma/Body Image					
Neurological-Quality of Life (Neuro-Qol) Stigma Measure	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Ages ≥18	Standardized	8
Body Image	All follow-ups, pre-burn (administered at discharge) or discharge	New	Proxy (ages 0–17); self-report (ages 8–17)	From Burn Outcomes Questionnaire	4
Domain: Itch					
4-Dimensional Itch Scale	Discharge and all follow-ups, not pre-burn (administered at discharge)	New	Ages ≥18	Standardized	4 (if participant reports itch)
Pain and Itch	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 0–7)	BMS	2
Itch (PROMIS items modified for the BMS)	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 0–17); self-report (ages 8–17)	BMS	4
Domain: Posttraumatic Stress Disorder					
Posttraumatic Stress Disorder Checklist	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Ages ≥18	Standardized	17
Child Posttraumatic Stress Disorder Symptom Scale	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Self-report (ages 8–17)	Standardized	24

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Domain: Drug/Alcohol/Medication Use					
CAGE Alcohol/Drug Use	Discharge and all follow-ups	Previously administered at discharge; now also administered at follow-ups	Ages ≥18	Standardized for alcohol; modified by BMS for drug use	8
Pain Medication	Pre-burn (administered at discharge) and all follow-ups	New	Proxy (ages 0–17); self-report (ages ≥13)	BMS	12 pain medications to read and check, if taking
Domain: Burn Specific Health					
Burn Specific Health Scale-Brief	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Ages ≥18	Standardized	40
Domain: Posttraumatic Growth					
Posttraumatic Growth Inventory	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Ages ≥18	Standardized	10
Posttraumatic Growth Inventory for Children	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Self-report (ages 8–17)	Standardized	10
Domain: Physical Function					
PROMIS Physical Function Mobility	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	8
PROMIS Physical Function Upper Extremity	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	8

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Pediatric Evaluation of Disability Inventory—Mobility	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 0–7)	Standardized	5
Domain: Satisfaction With Life/Positive Affect					
NIH TB General Life Satisfaction	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 3–17); self-report (ages 8–17)	Standardized	4
NIH TB Positive Affect	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 3–12); self-report (ages 13–17)	Standardized	4
Satisfaction With Life	Pre-burn (administered at discharge) and all follow-ups	Previously administered	Ages ≥18	Standardized	5

Using the Burn Model System National 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.

How Do You Request Data?

The following procedures have been designed to be simple, invite participation by external researchers, and maintain 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.
3. The BMS NDSC will share the form with the BMS project directors for their review
4. BMS project directors review for principal investigator (PI) affiliation, scientific purpose, and scientific overlap with existing approved projects.
5. BMS project directors will have 10 working days to provide comments; the NIDILRR BMS program manager will consider feedback from the BMS NDSC and BMS project directors when making a final decision regarding approval of the proposal.
6. 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.
7. Applicants have an option to propose or request a BMS researcher as a collaborator/consultant who is familiar with the data and the ways in which they are collected.

The typical turnaround time is 4–6 weeks from receipt of a new proposal to approval and release of data.