

Burn Model System Summary Report

1994–2019

This report contains information, tables, and figures about the data contained in the Burn Model System National Database, collected from 1993 to 2019. 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.



2020



Social Outcomes After Burn Injury	32
Employment Status and School Status.....	32
New Burn Model System Data Collection	33
Archived Burn Model System Data.....	39
Using the Burn Model System National Database.....	41
How Do You Request Data?.....	42
Burn Model System Data Collection Guidance.....	41

List of Figures

Figure 1. Number of Participants by Gender and Age Group	7
Figure 2. Distribution of Participants by Race.....	8
Figure 3. Geographical Location of Residence at Time of Burn Injury.....	9
Figure 4. Distribution of Adults Living With Another Person at the Time of Their Injury.....	10
Figure 5. Distribution of Children Living With Another Person at the Time of Their Injury.....	10
Figure 6. Number of Participants by Burn Size Category (% TBSA Burned)	13
Figure 7. Distribution of Participants by Cause of Injury.....	15
Figure 8. Number of Participants by Cause of Injury and Age Group.....	16
Figure 9. Distribution of Participants by Circumstance of Injury.....	17
Figure 10. Location of Injury Among Participants by Burn Size Category (% TBSA Burned)	18
Figure 11. Average Length of Acute Care Hospital Stay Among Participants by Year (1993–2016).....	19
Figure 12. Number of Participants and Days on Which They Spent on a Ventilator by Age Group.....	20
Figure 13. Distribution of Participants by Type of Disposition at Hospital Discharge.....	21
Figure 14. Number of Participants With Data at Long-Term Follow-Ups.....	25
Figure 15. Follow-Ups Completed by Racial/Ethnic Group.....	25
Figure 16. Mean Physical Function, Sleep, and Fatigue Scores by Time-point for Adult BMS Participants..	29
Figure 17. VR-12/SF12* Mental and Physical Health Scores By Time-point Among Adult BMS Participants and Norm Populations.....	31
Figure 18. Timeline of Burn Model System Variable and Measure Administration, Adults.....	39
Figure 19. Timeline of Burn Model System Variable and Measure Administration, Pediatrics.....	40

List of Tables

Table 1. Number and Percentage of Participants by Age Group.....	7
Table 2. Number and Percentage of Participants by Gender	8
Table 3. Number and Percentage of Participants by Ethnicity	8
Table 4. Type of Residence at the Time of Burn Injury.....	9
Table 5. Employment Status of Participants, 18 Years of Age and Older, at the Time of Their Injury	11
Table 6. School Status of Participants, 5–17 Years of Age, at the Time of Their Injury.....	11
Table 7. Pre-Injury Alcohol and Drug Use	11
Table 8. Pre-Injury Disability	12
Table 9. Pre-Injury Psychiatric Treatment.....	12

Table 10. Number and Percentage of Participants by Burn Size Category (% TBSA Burned).....	13
Table 11. Burn Injury Location.....	14
Table 12. Burn Graft Location.....	14
Table 13. Number and Percentage of Participants by Cause of Injury	15
Table 14. Number and Percentage of Participants by Circumstance of Injury	17
Table 15. Number and Percentage of Participants by Place of Injury.....	18
Table 16. Number and Percentage of Participants by Inhalation and Other Types of Injuries.....	18
Table 17. Percentage of Participants With Inhalation and Other Injuries by Gender	18
Table 18. Average Length of Acute Care Hospital Stay Among Participants by Burn Size Category (% TBSA Burned).....	19
Table 19. Number and Percentage of Participants Who Went to Inpatient Rehabilitation by Number of Days in Inpatient Rehabilitation.....	20
Table 20. Number and Percentage of Participants by Type of Disposition at Hospital Discharge.....	22
Table 21. Number and Percentage of Participants by Primary Sponsor of Care at Discharge.....	23
Table 22. Number and Percentage of Participants by Follow-Up Status and Time-Point	24
Table 23. Number and Percentage of Participants by Type of Surgery Since Last Follow-Up.....	26
Table 24. Number and Percentage of Participants by Therapy Use Since Last Follow-Up.....	26
Table 25. Physical Issues in Adults.....	27
Table 26. Physical Issues in Children.....	28
Table 27. Mean Physical Function, Sleep, and Fatigue Scores by Time-Point for Adult BMS Participants....	29
Table 28. Mean SF12/VR12 Scores Among Adult BMS Participants.....	30
Table 29. Employment Status After Burn Injury Among Adult Participants (≥ 18 Years of Age).....	32
Table 30. School Status After Burn Injury Among Child Participants (5–17 Years of Age)	32
Table 31. Summary of New BMS Data Collection Instruments and Measures	33

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), in the Administration of Community Living and the 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 (NWRBMS) in Seattle, Washington;
- Boston-Harvard Burn Injury Model System (BH-BIMS) in Boston, Massachusetts;
- Pediatric Burn Injury Rehabilitation Model System in Galveston, Texas; and
- North Texas Burn Rehabilitation Model System (NTBRMS) 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 6,500 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, 24 months, and every five years 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, 2019, the database contained information for 4,205 adults (18 years of age and older at the time of burn) and 2,321 children (17 years of age and younger at the time of burn).

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](#). Together, these partners help the BMS 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. The aim of this project is to create longitudinal social recovery trajectories using the LIBRE Profile. Established trajectories will promote determination of burn survivor needs on an individual and population basis, as well as foster the design and assessment of resources and interventions in these domains. This participatory action research project advances the NIDILRR Long-Range Plan by using a novel technology to improve community living and participation, and employment outcomes.

Project Director:

Jeffrey Schneider, MD

Project Manager:

Audrey Wolfe, MPH

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 1,900 participants since the BMS began. During the 2017-2022 funding cycle, the NTBRMS has a site-specific research study that examines Vitamin D deficiency in adult burn survivors. This study aims to compare low dose Vitamin D replacement to high dose to evaluate its effect on levels of Vitamin D in adult patients with major burn injury, and to determine if it improves common burn-related symptoms. The study will also examine if high dose vitamin D replacement has an impact on common symptoms experienced by burn patients such as fatigue, muscle weakness, pain, itch, and peripheral neuropathy as compared to low dose.

Project Director:

Karen Kowalske, MD

Project Co-Director:

Radha Holavanahalli, PhD

Pediatric Burn Injury Rehabilitation Model System

Shriners Hospital for Children in Galveston, and the University of Texas Medical Branch, have worked for more than 40 years to develop new interventions to improve the outcomes of children who have major burns. The population of patients who suffered burns have included persons from many countries and cultures who were referred to the hospital each year. Within the Shriners Hospital and the University of Texas Medical Branch (UTMB), the Pediatric Burn Injury Rehabilitation Model System has contributed to the overall research of the BMS program.

Project Director:

Steven Wolf, MD

Project Manager:

Oscar Suman, PhD

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 post-burn 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 examining virtual-environment home rehabilitation.

Project Director:

Nicole Gibran, MD

Project Manager:

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 Manager:

Kara McMullen, MPH

Summary of Burn Model System Findings 1994–2019

- 6,526 people consented to participate in the BMS database.
- 503 people died before hospital discharge.
- 1,062 people were eligible but did not agree to participate in the study.
- 71% of the participants in the database were male.
- 36% of the participants were younger than 18 years of age at the time of their burn injury.
- 71% of the participants were Caucasian; 17% were African-American; and 28% identified as Hispanic.¹
- Mean TBSA burned was 24% across all participants.
- 45% of participants had at least 20% TBSA burned.
- Length of acute care hospital stay averaged 26 days for participants younger than 18 years of age.
- Length of stay averaged 28 days for adults ages 18–30 years, 26 days for adults ages 31–45 years; 28 days for adults ages 46–64 years; 25 days for adults ages 65–74 years; and 27 days for adults ages 75 years and older.
- From 1994 to 2019, 676 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 2020.

Cause of Injury³

- Fire/flare: 59%
- 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., Heltsh, 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 ($n = 122$).

Demographics

Age Groups and Sex

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 38% 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 sex in the total sample.

Figure 1. Number of Participants by Sex and Age Group

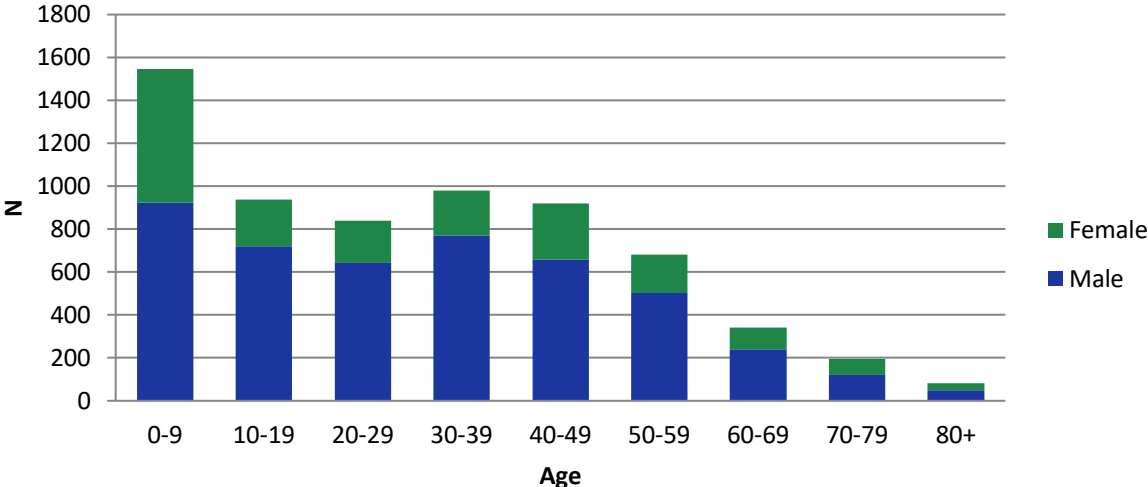


Table 1. Number and Percentage of Participants by Age Group

Age (Years)	Number of Participants	%
0-9	1,547	23.7
10-19	938	14.4
20-29	838	12.8
30-39	981	15.0
40-49	921	14.1
50-59	681	10.4
60-69	342	5.2
70-79	195	3.0
80+	83	1.3
Total	6,526	

Table 2. Number and Percentage of Participants by Sex

Sex	Number of Participants	%
Male	4,626	70.9
Female	1,900	29.1
Total	6,526	

Race and Ethnicity

Beginning in 2015, the BMS started collecting data on race and ethnicity in a way that more closely resembles the U.S. Census Bureau data collection for these variables. 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 4.7% 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

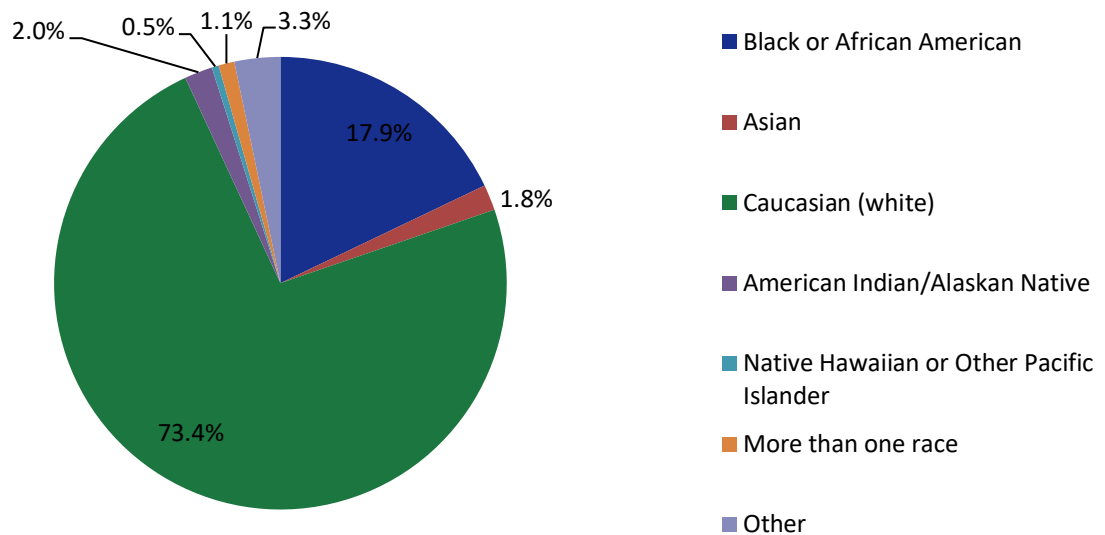


Table 3. Number and Percentage of Participants by Ethnicity

Ethnicity	Number of Participants	%
Hispanic or Latino	1,763	27.0
Not Hispanic or Latino	4,457	68.3
Missing/unknown	306	4.7
Total	6,526	

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 9% 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	5,837	89.4
Homeless	66	1.0
Missing/unknown	623	9.5
Total	6,308	

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

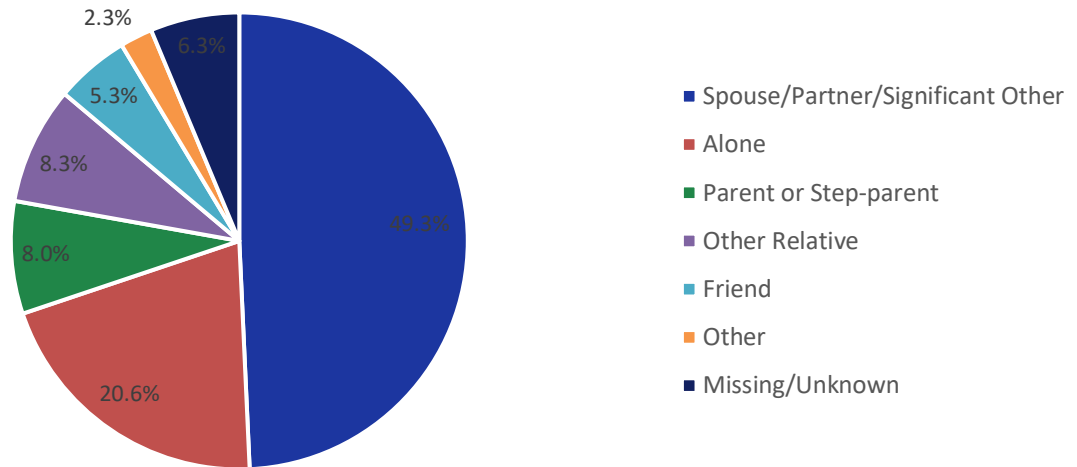
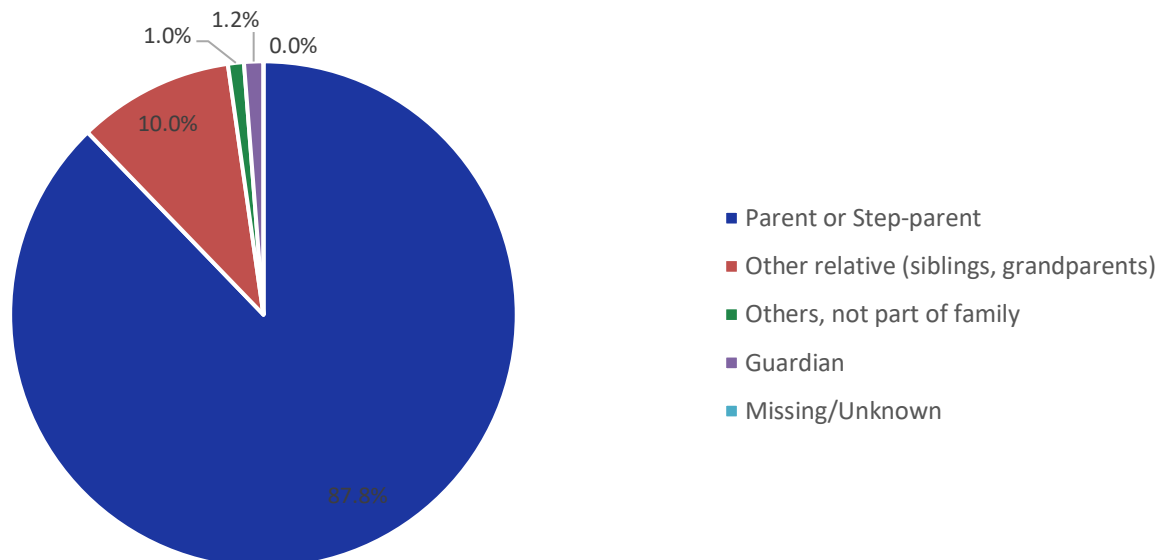


Figure 5. Distribution of Children Living With Another Person at the Time of Their Injury



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 ($n = 4,205$). 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 ($n = 1,269$). 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	2,609	62.0
Not employed	1,006	23.9
Retired	420	10.0
Homemaker/caregiver	51	1.2
Volunteer	8	0.2
Missing/unknown	111	2.6
Total	4,205	

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

School Status	Number of Participants	%
In school	1,093	87.4
Not in school	176	14.1
Missing/unknown	0	0.0
Total	1,250	

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 7.5% 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	559	14.8%
Drug use indicating a potential problem in past 12 months	431	11.2%

Participants Reporting Pre-Existing Physical Problems

Table 8 identifies the prevalence of physical problems (such as a mobility impairment or difficulty moving their arms, legs, or body) before the burn injury among participants in the BMS database. This data point was added to data collection forms in 2015 and therefore has a smaller n than other BMS data points. The percentage represents the rate of those with data for this data point (19.6% of the records collected since 2015 have missing data for this item).

Table 8. Pre-Injury Disability

Disability	Number of Participants	%
Pre-injury physical disability	122	15.4

Participants Reporting Incarceration

Table 9 identifies the prevalence of incarceration before the burn injury among participants in the BMS database. This data point was added to data collection forms in 2015 and therefore has a smaller n than other BMS data points. The percentage represents the rate of those with data for this data point (21.5% of the records collected since 2015 have missing data for this item).

Table 9. Pre-Injury Incarceration

Incarceration	Number of Participants	%
Incarceration for conviction of felony	48	8.7

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, 52.0% of participants had less than 20% TBSA burned. Only 7.6% 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)

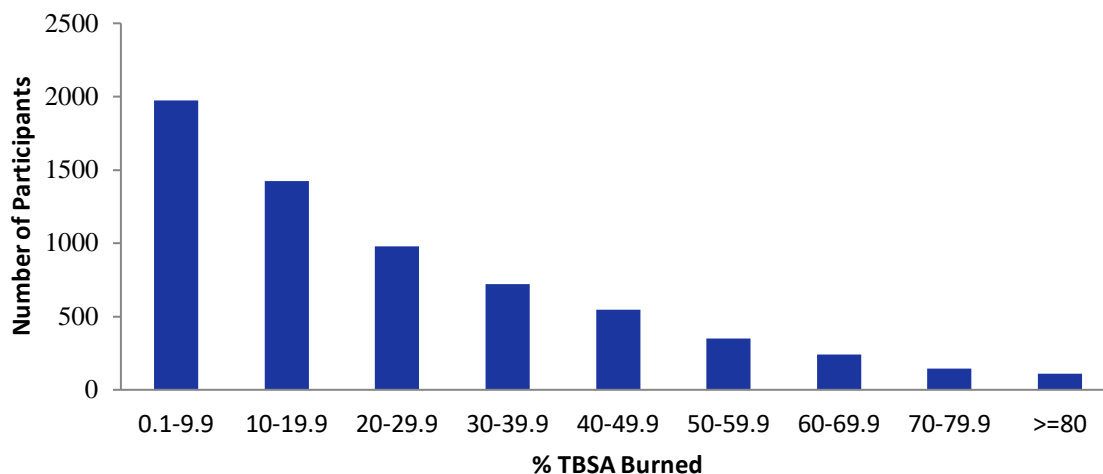


Table 10. Number and Percentage of Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Number of Participants	%
0.1-9.9	1,972	30.2
10-19.9	1,422	21.8
20-29.9	978	14.9
30-39.9	721	11.1
40-49.9	547	8.4
50-59.9	352	5.4
60-69.9	239	3.7
70-79.9	145	2.2
>=80	111	1.7
Missing/unknown	39	0.6
Total	6,526	

Burn Location and Graft Location on the Body

Table 11 presents data on the bodily location of burn injuries for participants in the BMS database while Table 12 presents data on the bodily location of grafting.

Table 11. Burn Injury Location

Location	Yes	%	Missing/Unknown	%
Head/neck burn	3,602	55.2	2,851	43.7
Trunk burn	4,068	62.3	2,396	36.7
Perineum burn*	1,075	16.5	4,908	75.2
Arm burn (right, left, or bilateral)	4,573	70.1	1,861	28.5
Hand burn (right, left, or bilateral)	4,329	66.3	2,122	32.5
Leg burn (right, left, or bilateral)	3,853	59.0	2,610	40.0
Foot burn (right, left, or bilateral)	2,103	32.2	4,333	66.4

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

Table 12. Burn Graft Location

Location	Yes	%	Missing/Unknown	%
Head/neck graft	1,211	18.6	5,151	78.9
Trunk graft	2,537	38.9	3,840	58.8
Perineum graft*	510	7.8	5,266	80.7
Arm graft (right, left, or bilateral)	3,232	49.5	3,207	49.1
Hand graft (right, left, or bilateral)	2,804	43.0	3,557	54.5
Leg graft (right, left, or bilateral)	2,872	44.0	3,511	53.8
Foot b graft (right, left, or bilateral)	1,474	22.6	4,875	74.7

*The variable assessing perineum graft 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 with data on this topic. Data on cause of injury among participants were unknown or not recorded for 1.9% of the records in the database. Among participants with available data, 59.3% were injured by fire/flame. Table 13 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

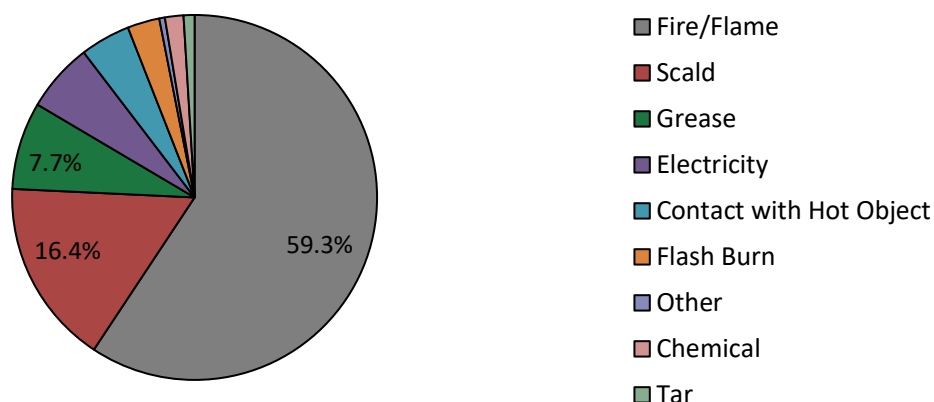
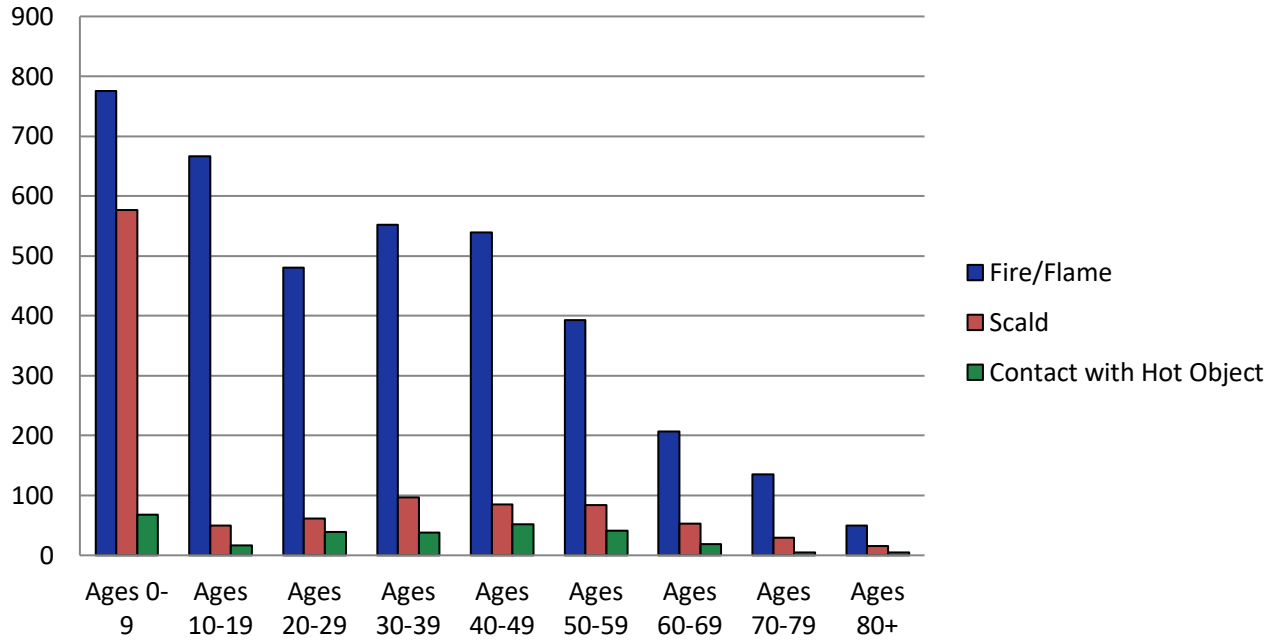


Table 13. Number and Percentage of Participants by Cause of Injury

Cause of Injury	Number of Participants	%
Fire/Flame	3,798	58.2
Scald	1,053	16.1
Grease	496	7.6
Electricity	392	6.0
Contact with Hot Object	284	4.4
Flash Burn	182	2.8
Chemical	32	0.5
Tar	105	1.6
Other	62	1.0
Unknown/Missing	122	1.9
Total	6,526	

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



Circumstances and Place of Injury

Table 14 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 2.1% 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 15 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 14. Number and Percentage of Participants by Circumstance of Injury

Circumstance of Injury	Number of Participants	%
Non-intentional non-work related	3,341	51.2%
Non-intentional employment related	1,043	16.0%
Non-intentional recreation	876	13.4%
Non-intentional unspecified	734	11.2%
Suspected self-inflicted/suicide	147	2.3%
Suspected assault--domestic	142	2.2%
Suspected assault--non-domestic	83	1.3%
Suspected arson	21	0.3%
Missing/unknown	139	2.1%
Total	6,526	

Figure 9. Distribution of Participants by Circumstance of Injury

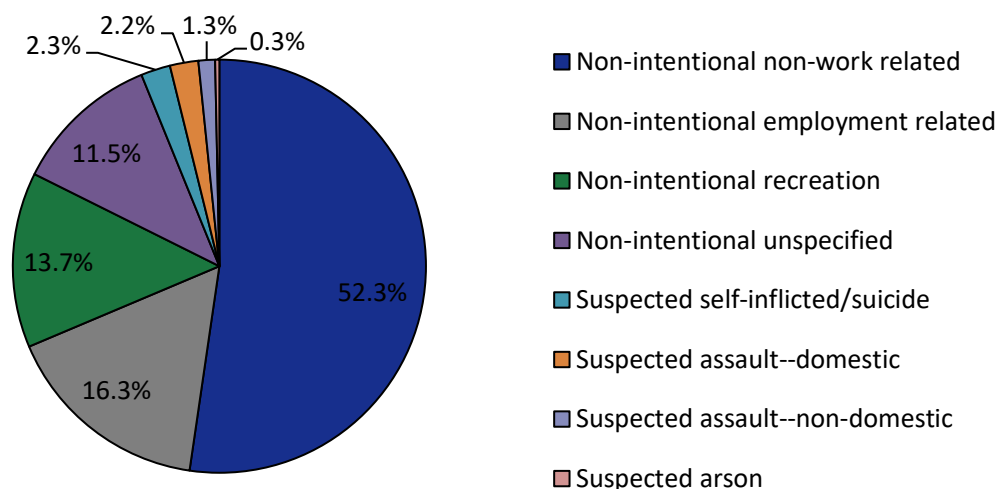
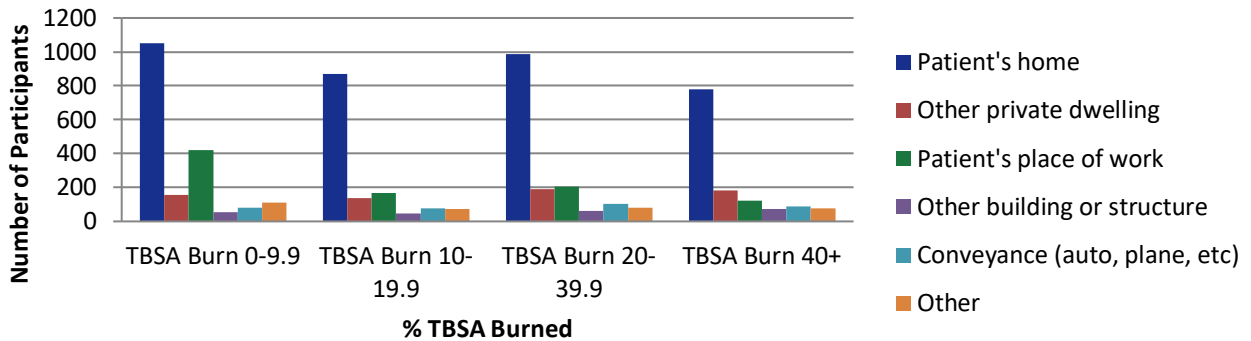


Table 15. Number and Percentage of Participants by Place of Injury

Place of Injury	Number of Participants	%
Closed/Indoors	3,821	58.6
Open/outdoors	2,511	38.5
Missing/unknown	194	3.0
Total	6,526	

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



Inhalation and Other Injuries

Table 16 identifies the incidence of inhalation injuries and other injuries among participants in the BMS database, as well as range of motion deficits. Table 17 provides data on inhalation and other injuries by gender (based on available data).

Table 16. Number and Percentage of Participants by Inhalation and Other Types of Injuries

Type of Injury	Number of Participants	%
Inhalation injury	988	15.4
Other injury	794	12.5
Range of motion deficit	3,167	53.9

Table 17. Percentage of Participants With Inhalation and Other Injuries by Gender

Gender	Inhalation Injury %	Other Injuries %
Males	14.9	13.0
Females	16.9	11.3

Treatment Before Discharge

Length of Acute Care Hospital Stay

Figure 11 shows the average length of acute care hospital stay at the BMS Center per year among participants in the BMS database. Only 20 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 2019, the average length of stay was 27 days. Length of stay varies across years, with no downward or upward trend. The criteria for the database changed in 2005 to include more severe burns. Table 18 shows the average length of hospital stay by percent TBSA burned.

Figure 11. Average Length of Acute Care Hospital Stay Among Participants by Year (1993–2019)

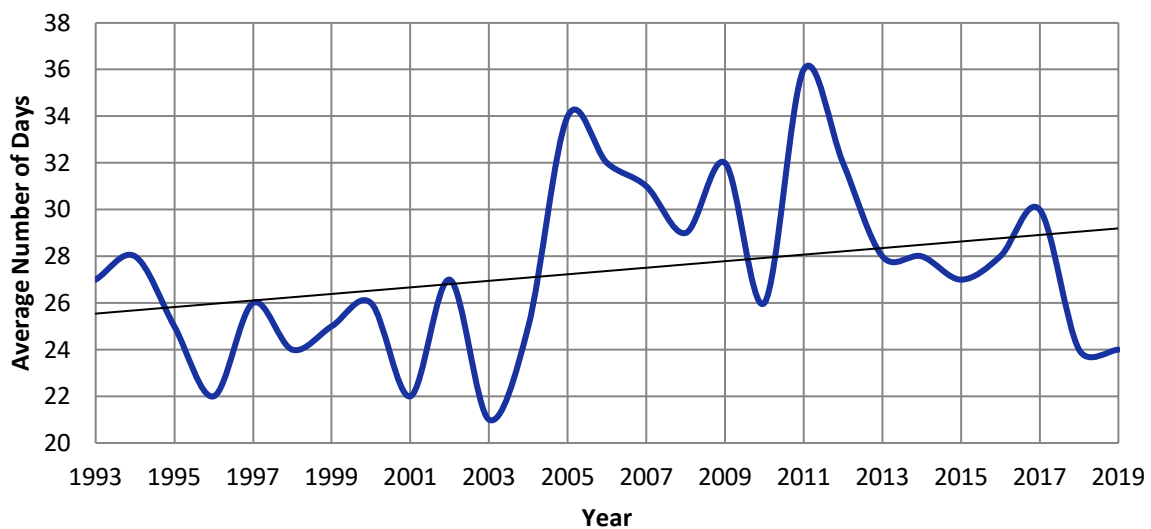


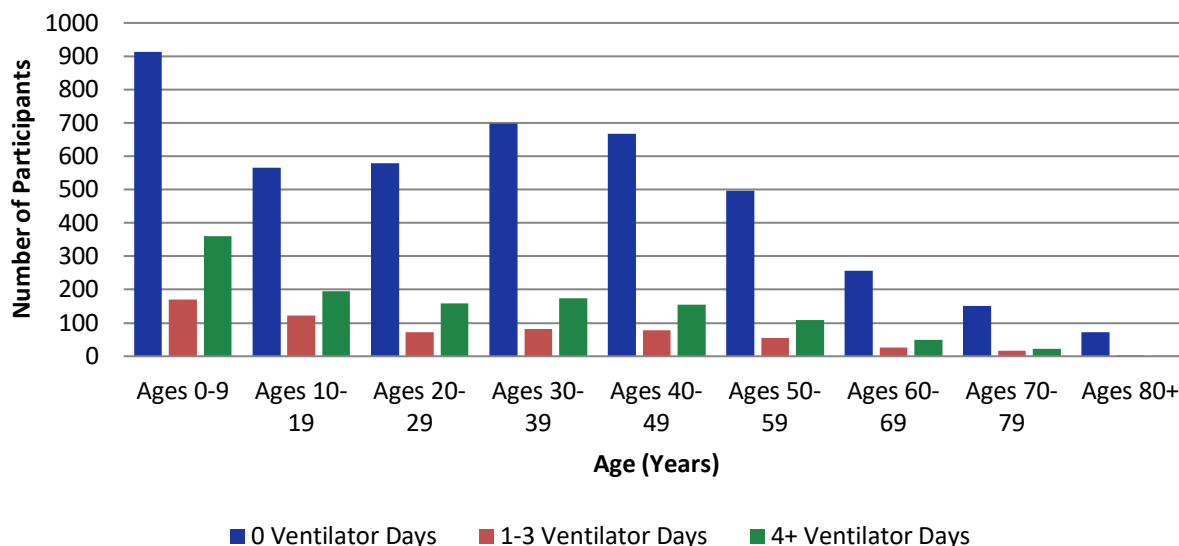
Table 18. Average Length of Acute Care Hospital Stay Among Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Average Length of Hospital Stay (Days)
0–9.9	14.0
10–19.9	19.4
20–29.9	25.6
30–39.9	31.3
40–49.9	38.1
50–59.9	41.7
60–69.9	52.4
70–79.9	64.6
≥80	106.4

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 4.2% 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 19 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 19. 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)	4,488	86.3
1–10 days of rehab	165	3.2
11–20 days of rehab	240	4.6
≥21 days of rehab	272	5.2
Missing/unknown	35	0.7
Total	5,199	

*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 20 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

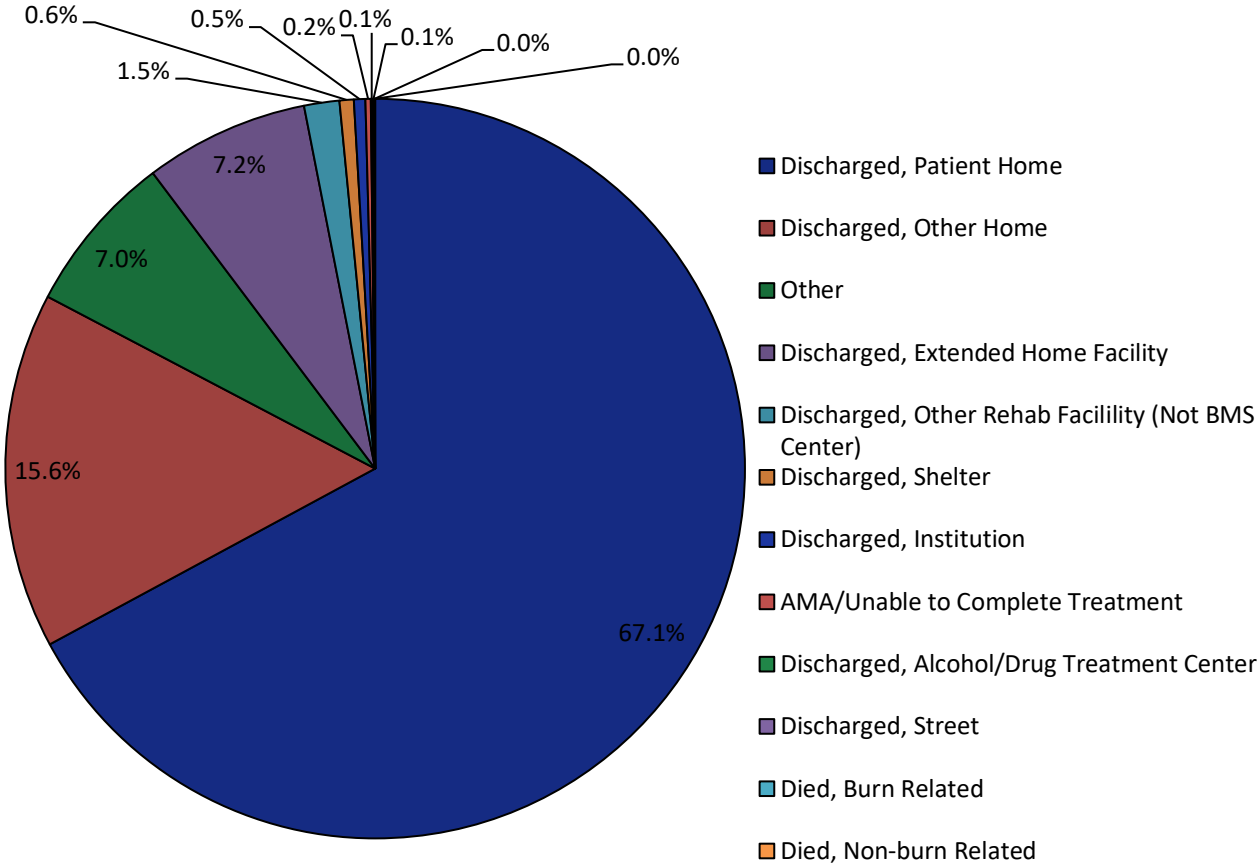


Table 20. Number and Percentage of Participants by Type of Disposition at Hospital Discharge

Disposition	Number of Participants	%
Discharged, patient home	4,309	66.0
Discharged, other home	1,000	15.3
Discharged, extended home facility	461	7.1
Other	452	6.9
Discharged, other rehab facility (not BMS Center)	99	1.5
Discharged, shelter	40	0.6
Discharged, institution	32	0.5
Unable to complete treatment	15	0.2
Discharged, alcohol/drug treatment center	5	0.1
Discharged, street	5	0.1
Died, burn related	1	0.0
Died, not burn related	1	0.0
Missing/unknown	106	1.6
Total	6,526	

Primary Sponsor of Care at Discharge

Table 21 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 almost 11% of the records in the database.

Table 21. Number and Percentage of Participants by Primary Sponsor of Care at Discharge

Primary Sponsor of Care at Discharge	Number of Participants	%
Private Insurance/HMO/PPO/Pre-paid/Managed Care	1,517	24.1
Philanthropy (private support)	1,074	17.0
Medicaid	928	14.7
Worker's compensation	676	10.7
Other	528	8.4
Medicare	541	8.6
Self-pay (public support)	528	8.4
Champus/Tri-Care	28	0.4
VA	27	0.4
Missing/Unknown	679	10.8
Total	6,526	

Status of Follow-Up Assessment

Table 22 identifies the number and percentage of each type of follow-up status at 6, 12, and 24 months. Data consist of all participants for whom data collection at that time-point is due (i.e., for the 24 months column, participants are included who were burned up to the year 2017). Figure 14 identifies the number of completed follow-ups at longer term time-points (i.e., 5, 10, and 15 years post-burn). Full-scale data collection for these time-points began in 2015 (some data was previously collected as a module project) and, for some centers, requires the participant to re-consent to the study before they provide any follow-up data. Figure 15 shows follow-ups completed by racial/ethnic group and is based on available data.

Table 22. Number and Percentage of Participants by Follow-Up Status and Time-Point

Follow-Up Status	6 Months		12 Months		24 Months	
	Number of Participants	%	Number of Participants	%	Number of Participants	%
Data collected/Follow-up Complete	4,569	77.1	4,058	75.8	3,431	68.3
Death due to burn-related complications	15	0.3	12	0.2	10	0.2
Death due to non-burn complications	26	0.4	48	0.9	68	1.4
Unable to locate	389	6.6	430	8.0	670	13.4
Refused this assessment	56	0.9	48	0.9	88	1.8
Unable to test/medically incapable of responding	15	0.3	22	0.4	30	0.6
Failed to respond	782	13.2	626	11.7	609	12.1
Did not consent to future assessment/withdrew	49	0.8	65	1.2	74	1.5
Incarcerated	6	0.1	23	0.4	24	0.5
Still in hospital (not discharged yet)	10	0.2	1	0.02	0	0
Other	12	0.2	13	0.2	8	0.2

Figure 14. Number of Participants With Data at Long-Term Follow-Ups

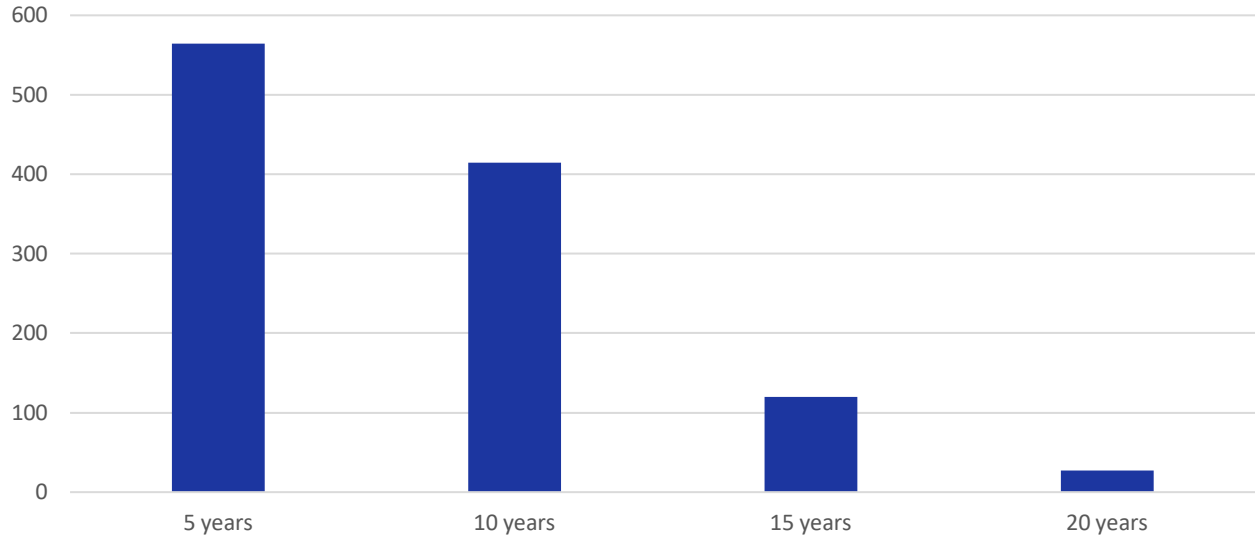
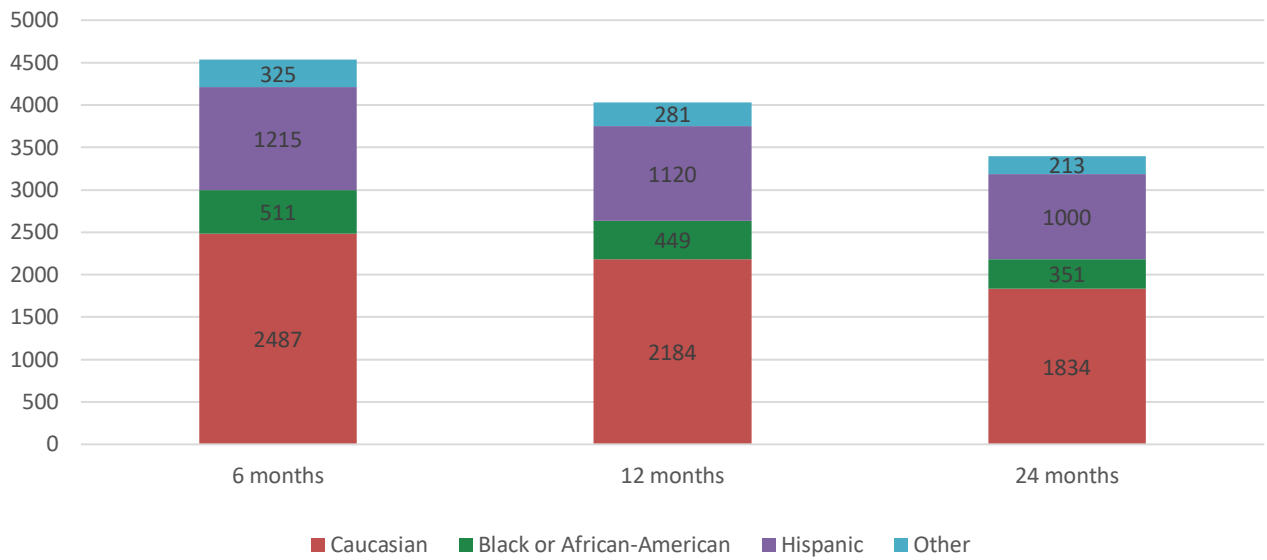


Figure 15. Follow-Ups Completed by Racial/Ethnic Group



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 with follow-ups collected since 2009 ($n = 2,028$). Percentages reflect only available data.

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	275	15.1	321	17.6	310	17.3
Surgery for open wounds**	91		62		48	
Surgery for joint contractures**	132		166		164	
Surgery for scar management**	145		189		204	

*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*	843	49.4	566	36	346	24.5
Psychological or peer support therapy**	97	20.3	76	18.1	69	18.3

*Data collection for these variables began in 2009.

**Data collection for this variable began in 2015

Physical Outcomes After Burn Injury

Physical Issues in Adults

Table 25 presents data on various physical issues among adults in the BMS database at four time-points post-burn. Data on these variables have only been collected since 2015; therefore this data applies to only those adult participants with data collected since 2015. Percentages reflect participants for whom there is data for these physical issues.

Table 25. Physical Issues in Adults After Burn Injury

Physical Issues*	6 Months		12 Months		24 Months		5 years	
	N	%	N	%	N	%	N	%
Hearing loss	67	15.7	50	13.4	56	17.1	18	15.9
Change in voice	50	11.7	39	10.4	37	11.4	18	15.5
Vision problems not corrected by contacts or glasses	56	13.0	45	12.0	29	8.8	18	15.5
Eyelid problems	29	6.8	17	4.5	20	6.1	7	6.0
Excessive tearing of the eyes	37	8.7	44	11.7	33	10.1	10	8.6
Difficulty with memory	118	27.7	104	27.7	90	27.7	39	34.2
Difficulty with thought processing	92	21.4	82	21.8	78	24.2	29	25.0
Numbness, pins and needles or burning sensations in burn scar	297	68.1	233	60.5	160	48.1	62	53.5
Numbness, pins and needles or burning sensations in hands	199	46.4	148	39.1	111	33.5	47	40.2
Numbness, pins and needles or burning sensations in feet	131	30.6	105	27.9	84	25.4	32	27.6
Trouble with balance	114	26.5	94	24.9	85	25.9	41	35.0
Varicose veins	45	10.7	35	9.5	32	9.9	10	8.7
Swollen feet or legs	109	25.4	84	22.4	68	20.5	31	26.3
Swollen hands or arms	62	14.7	33	8.8	33	9.9	10	8.6
Difficulty with breathing when doing regular activities	76	17.7	76	20.1	58	17.6	22	18.6
Skin cancer	5	1.2%	81	2.2	7	2.2	2	1.8%

*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 five time-points post-burn. Data on these variables have only been collected since 2015; therefore this data applies to only those pediatric participants with data collected since 2015. 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 After Burn Injury

Problems with...	6 Months		12 Months		24 Months		5 years		10 years	
	N	%	N	%	N	%	N	%	N	%
Seeing	13	6.4	17	9.2	17	9.1	23	23.0	23	39.7
Hearing	4	2.0	3	1.6	10	5.4	7	7.0	8	13.8
Learning and understanding	16	8.0	16	8.7	32	17.2	24	24.2	6	10.3
Controlling emotions or behavior	70	34.8	49	26.8	58	31.2	37	37.0	16	27.6
Sleeping	12	6.0	12	6.5	5	2.7	10	10.0	1	1.7
Breathing	18	9.0	10	5.4	9	4.9	8	8.0	1	1.7
Chronic open skin areas	36	17.8	32	17.2	21	11.2	8	8.0	4	6.9
Other skin problems	22	11.1	16	8.7	20	10.8	6	6.0	3	5.2

Physical Function, Sleep, and Fatigue among Adults

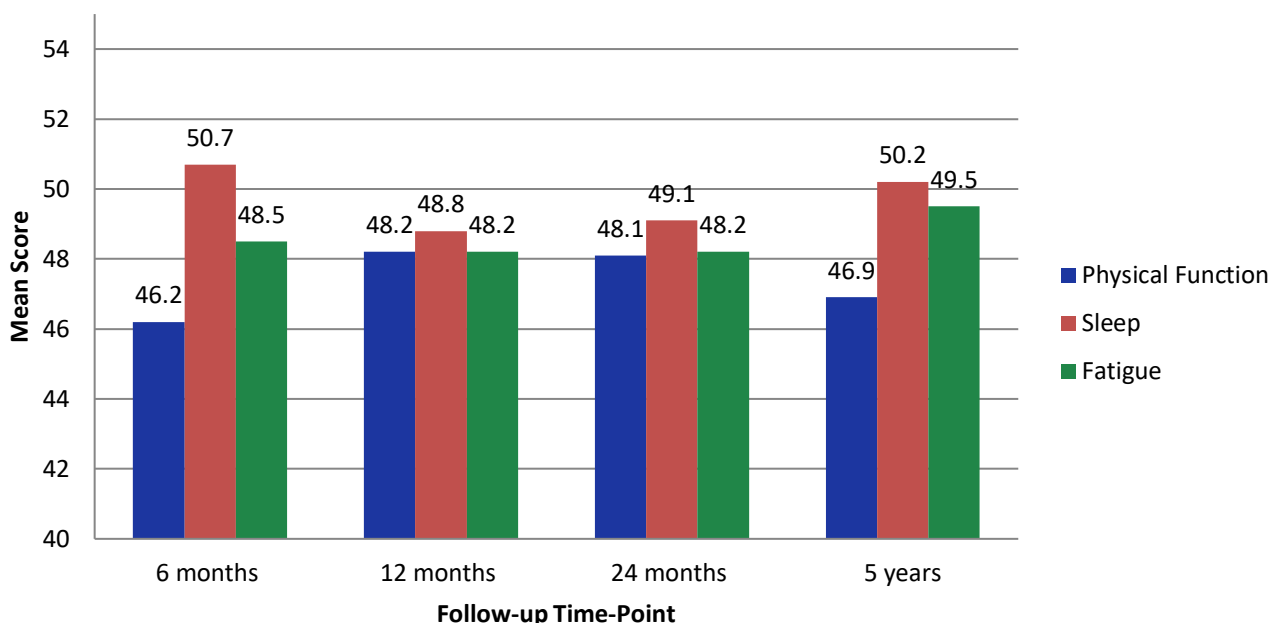
Table 27 presents data on the physical function, sleep, and fatigue scores among adult participants in the BMS database at three time-points. These problems are assessed using the PROMIS-29 scale⁴, which collects data on several areas of functioning and then provides norm scores that can be compared 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 adult participants with follow-up data collected since 2015. Figure 16 shows mean pain, itch, and sleep problems by cross-sectional time point. Over time, problems with pain or sleep remain relatively constant, while problems with itch trend downward. These are trends in the data as a whole and do not necessarily represent individual participant experience or repeated measures.

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

	6 Months		12 Months		24 Months		5 years	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Physical Function	46.2 (9.9)	410	48.2 (9.7)	369	48.1 (9.7)	329	46.9 (9.9)	115
Sleep	50.7 (10.5)	416	48.8 (10.5)	371	49.1 (10.8)	330	50.5 (9.2)	118
Fatigue	48.5 (11.8)	413	48.2 (11.7)	369	48.2 (11.3)	321	49.5 (11.2)	117

*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

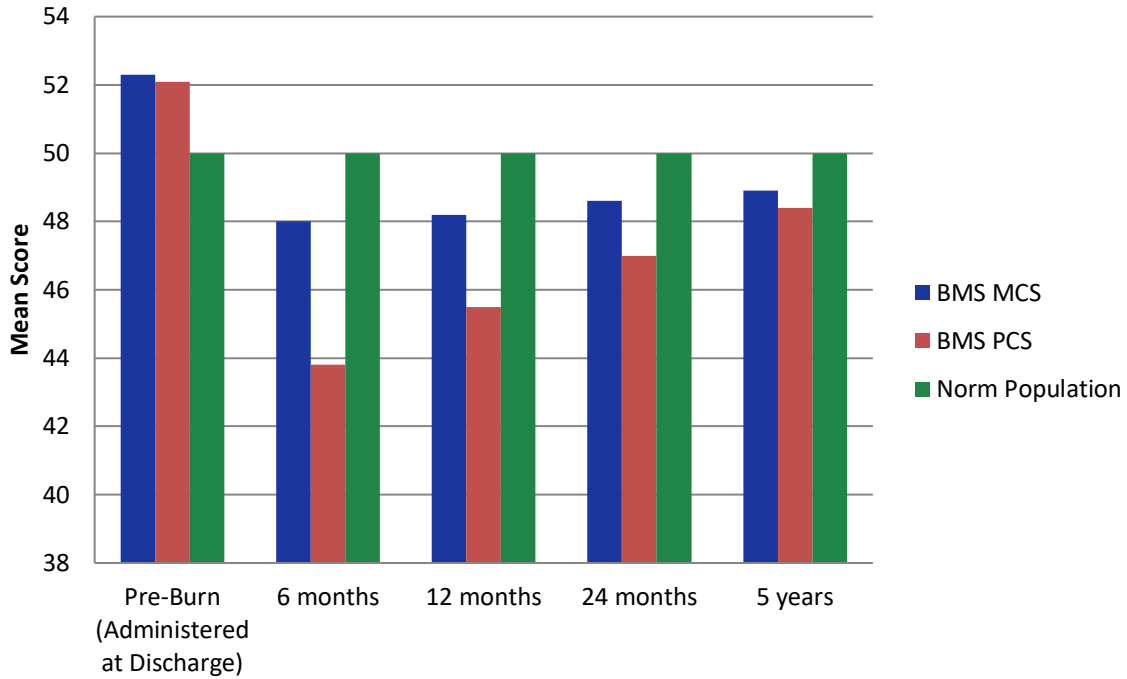
Table 28 presents the mean VR12/SF-12 Mental Health Component (MCS) and Physical Health Component (PCS) scores for adult participants, in the BMS database at each follow-up time-point. The SF12/VR-12 are sets of questions that clinicians ask patients to understand how people are doing physically and 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 cross-sectionally by time-point.

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

Mean VR-12/SF12* Scores, Adults	Pre-Burn (Administered at Discharge)		6 Months		12 Months		24 Months		5 Years	
	Mean	N	Mean	N	Mean	N	Mean	N	Mean	N
MCS	52.3	2,539	48.0	1,789	48.2	1,653	48.6	1,433	48.9	341
PCS	52.1	2,539	43.8	1,789	45.5	1,653	47.0	1,433	48.4	341

*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 17. VR-12/SF12* Mental and 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 over the age of 18 (65 and up included due to option for retirement) in the BMS database ($n = 4,205$), and is based on only available data. Table 30 presents data on the post-injury school status at follow-up of children, 5–17 years of age, in the BMS database ($n = 1,224$). Like employment status for adults, data on school status among children have not been collected during the entire span of the BMS. Therefore, Table 30 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	1,199	35.2	1,238	41.1	1,134	44.6
Not Working	1,849	54.3	1,439	47.8	1,121	44.1
Homemaker/Caregiver	35	1.0	34	1.2	31	1.2
Volunteer	18	0.5	9	0.3	11	0.4
Retired	303	8.9	290	9.6	245	9.6

*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	494	81.6%	505	81.8%	488	81.7%
Not school	118	21.0%	113	21.3%	113	21.7%

*Data collection for these variables began in 2009.

Burn Model System Data Collection Additions

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

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Burn Injury Follow-Up	All follow-up points, not pre-burn (administered at discharge) or discharge	Some items are new, such as the primary transportation. Some have been previously collected, such as physical or psychological therapy.	Proxy (ages 0–17); self-report (ages ≥13)	BMS	15
Domain: Medical Conditions					
Review of Systems	Pre-burn (administered at discharge), discharge, and all follow-ups	New	Ages ≥18	BMS	21
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), 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

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
Domain: Community Participation					
Community Integration Questionnaire	Pre-burn (administered at discharge) and all follow-ups	Previously administered	Ages ≥14	Standardized	6
PROMIS Peer Relationships	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 8–17)	Standardized	7
Domain: Depression					
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: 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
Pediatric Evaluation of Disability Inventory—Mobility	All follow-ups, not pre-burn (administered at discharge) or discharge	New	Proxy (ages 0–7)	Standardized	5

Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
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
Satisfaction With Life	Pre-burn (administered at discharge) and all follow-ups	Previously administered	Ages ≥18	Standardized	5

Archived Burn Model System Data

The Burn Model System has collected many other measures in addition to those represented in this report since 1993. Figure 18 and Figure 19 represent what data have been collected, and when, for adults and pediatrics, respectively.

Figure 18. Timeline of Burn Model System Variable and Measure Administration, Adults

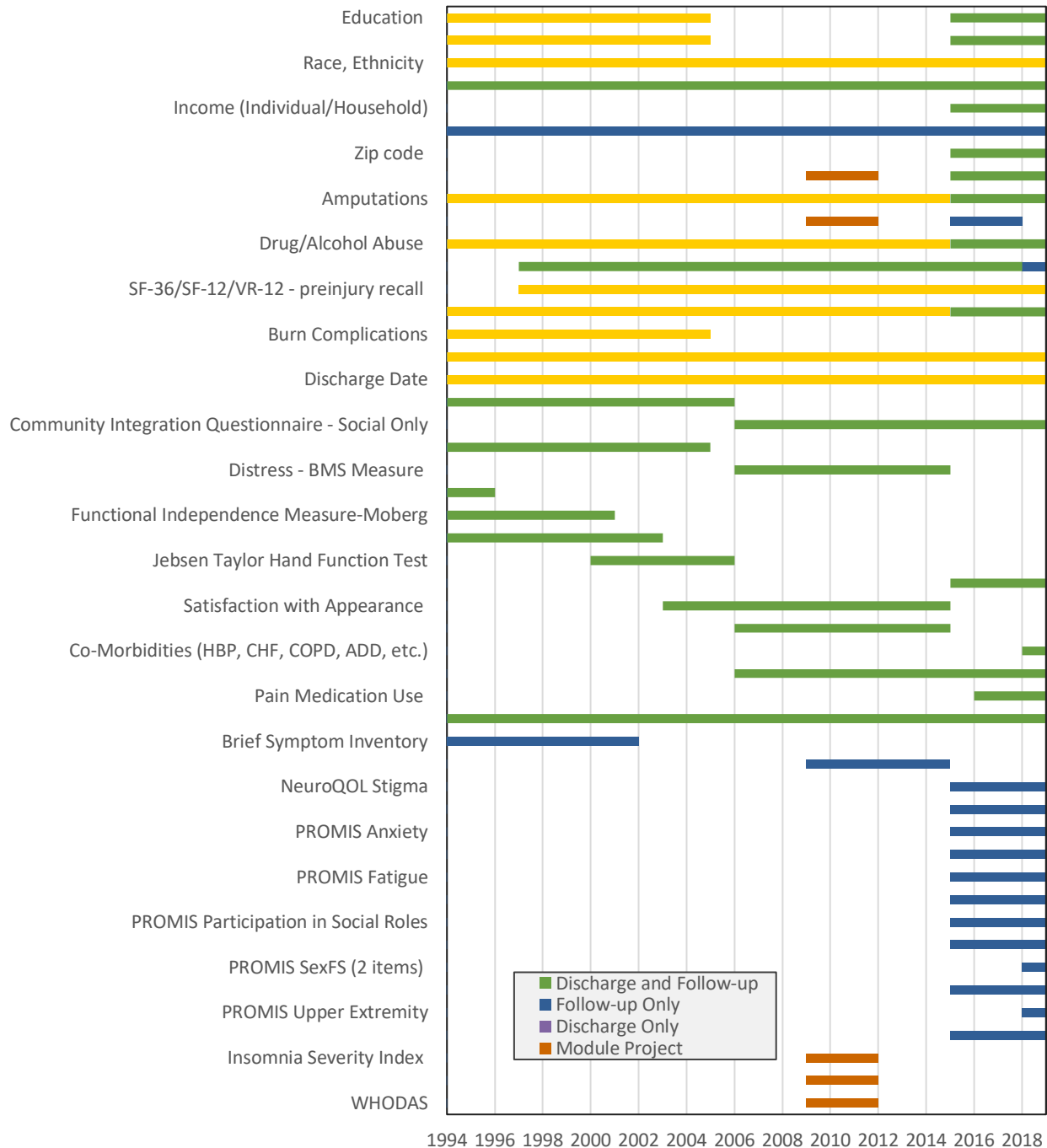
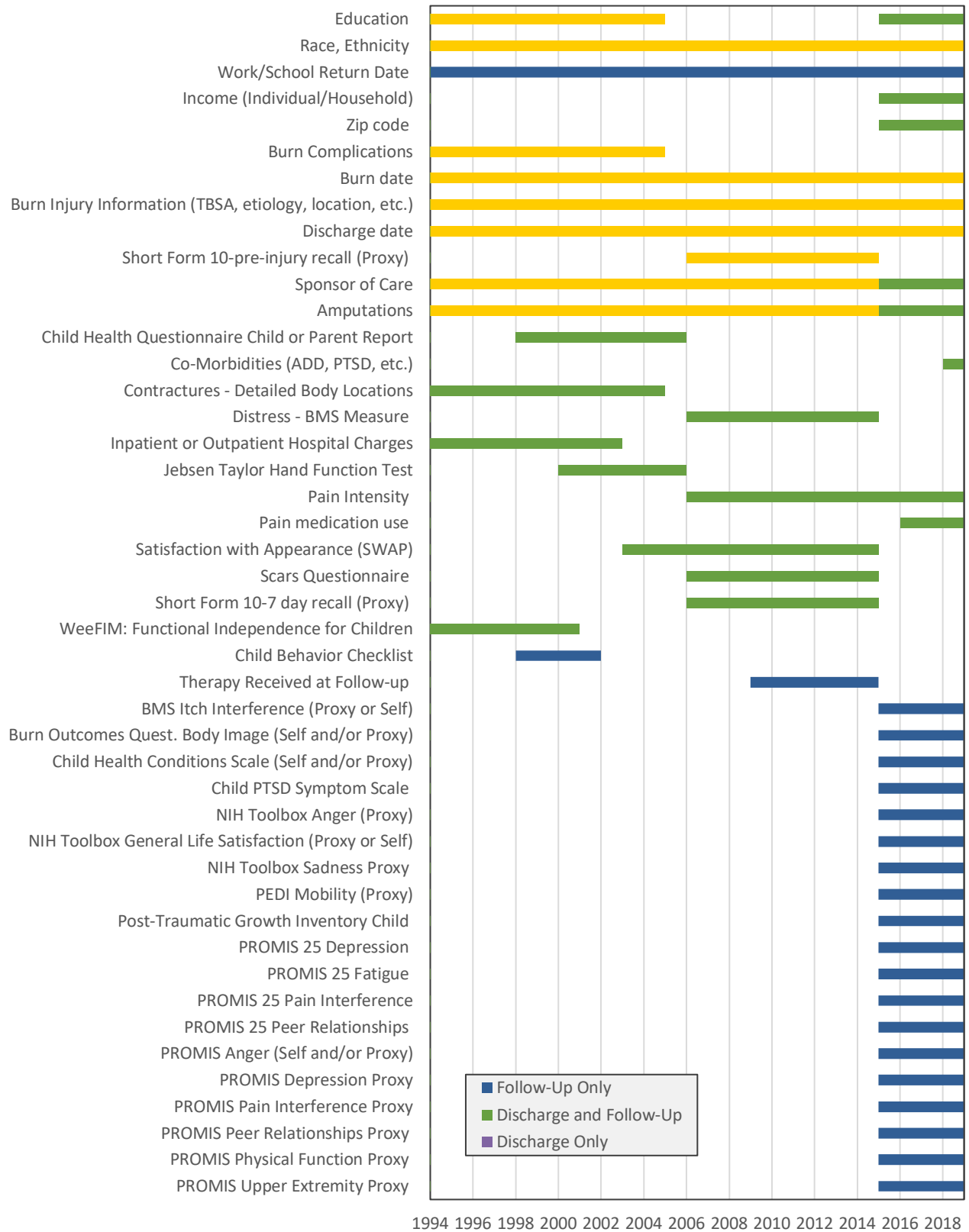


Figure 19. Timeline of Burn Model System Variable and Measure Administration, Pediatrics



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.



What Are the Two Types of BMS Data Access?

Annually Published Public Access

The Public Dataset is published annually and contains data collected up to two years prior to its publication date. Data are stripped of all HIPAA-defined identifiers, including names, geographic subdivisions smaller than a state, elements of dates (except year) related to an individual, telephone numbers, fax numbers, email addresses, social security numbers, and medical record numbers.

Custom Data Access

A Custom Data Set includes all available data (i.e., all data available at the time of request), and is available free of charge to researchers with specific hypotheses who might want BMS input or collaboration.

What Is the Difference Between Annually Published and Custom Datasets?

The Annually Published Dataset includes:

- **All** BMS data available except identifiers
- Data collected up to 2 years prior to the publication date, i.e., data in the dataset is **older** than 2 years before the publication date

A Custom Dataset includes:

- Only variables you request and are necessary to answer your research question(s)
- Most recent data available at the time of request

Both datasets:

- Contain de-identified data
- Require users to agree to a data use agreement

How to Request BMS Datasets

Annually Published Public Dataset

1. Contact the BMS National Data and Statistical Center (NDSC) (burndata@uw.edu) to request the Public Dataset. In your email, specify the file type you prefer (e.g., Excel, SPSS, SAS).
2. The NDSC will respond within 24 hours by sending you a data use agreement;
3. Agree to the terms of data use via return email and the BMS NDSC will send you a de-identified dataset via secure file storage within 5-10 business days

Custom Dataset:

1. Formulate your research question(s) and hypotheses. Review the list of papers already published (<http://burndata.washington.edu/pubs>) or in progress (<http://burndata.washington.edu/publications-progress>) to make sure your research questions have not already been addressed.
2. Review the variables in the database. Pay close attention to whether the variables you are interested in are available at the time points of interest;
3. Download and fill out a Data Request and Use Agreement Form from <http://burndata.washington.edu/sites/burndata/files/files/DataAgreementForm.pdf>. Email the completed forms to the BMS NDSC at burndata@uw.edu.
4. The BMS reviews the scientific purpose and scientific overlap with existing projects and approves the request (typically within 2 weeks).
5. Once approved, the BMS NDSC will provide a de-identified dataset and assist with any questions you have about the dataset free of charge.
6. Provide annual updates on progress of the project, and an updated anticipated completion date.

Resources available to you at <http://burndata.washington.edu/about-database>:

- Overview of available variables (pdf download)
- Database Data Dictionary with detailed information on all variables: (excel file download)
- A BMS Database Introduction PowerPoint Presentation

Burn Model System Data Collection Guidance

Introduction

The BMS make their data collection forms public in order for external researchers to benefit from the BMS' years of discussion and experience with the data collection forms. They provide the following guidance for researchers, clinicians or other entities interested in using the BMS data collection forms for their data collection.

If you are interested in a formal, BMS-approved collaboration, see SOP #611, located online at the webpage: <https://burndata.washington.edu/standard-operating-procedures>. If you are interested in replicating the data collection of the BMS, following BMS procedures but have no interest in a formal, BMS-approved collaboration, please refer to the following guidance:

Collecting & Coding Data

1. The BMS Data Collection forms (i.e., questionnaires) are located online at <https://burndata.washington.edu/about-bms> and include questions for data to collect from burn survivors at hospital discharge and at follow-up time-points. Please note, the discharge and follow-up forms have different version for use with adults, pediatric self-report, and pediatric proxy (i.e., a report by a parent or care giver). These forms are available in English and Spanish.
2. The BMS collect follow-up data at hospital discharge, 6-months post-injury, 12-months post-injury, 24-months post-injury, and every 5 years post injury⁵.
3. The BMS Standard Operating Procedures (SOPs) provide specific information about BMS inclusion and exclusion criteria for participants (SOP #101), guidelines for participant recruitment and consent (SOP #102), follow-up of participants (SOPs #103 & #105), and data quality guidelines (SOP #104). These SOPs can be found at this webpage: <https://burndata.washington.edu/standard-operating-procedures>.
4. Coding of each data point, along with some information on scoring and guidance for data collectors, is provided in the BMS Data Dictionary, which can be found at the webpage <https://burndata.washington.edu/about-database> under the heading titled "For Researchers Interested in the Data."

Scoring Data

In recent years, the Burn Model System has moved toward the use of standardized, publicly available measures, so that the instruments and scoring algorithms are accessible to all with no licensing fees. Below are links for more information about the main outcome measures collected by the BMS:

1. PROMIS-29, PROMIS-25, NIH Toolbox and NeuroQOL measures: <http://www.healthmeasures.net/explore-measurement-systems/overview>
2. Satisfaction with Life Scale (SWL): <https://www.sralab.org/rehabilitation-measures/satisfaction-life-scale>
3. Community Integration Questionnaire Social Integration Subscale (CIQ SIC)

⁵ Post-injury date is calculated based on the burn date, not hospital consent date.

- <https://www.sralab.org/rehabilitation-measures/community-integration-questionnaire>
4. VR-12: https://www.rand.org/pubs/research_reports/RR1844.html
 5. Post-Traumatic Check-List-Civilian (PCL-C) <https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp#obtain>
 6. Post-Traumatic Growth Inventory (PTGI): <https://www.emdrhap.org/content/wp-content/uploads/2014/07/VIII-B-Post-Traumatic-Growth-Inventory.pdf>

Utilizing BMS Data

If you collect data using the BMS data collection forms and would like to combine your and the BMS's data for a study, there are two options to access the BMS data. These options are briefly described below. More information is available at: <https://burndata.washington.edu/about-database>

1. Access the BMS Public Dataset, which is always available and contains data collected more than two years prior to the publication date. This dataset is located at: <https://burndata.washington.edu/about-database>
2. Request a customized dataset from the BMS. This option provides you with a dataset that includes only the variables you request for your specified years. This dataset option can include the most current data, and provides you with some technical assistance from the BMS NDSC.

Please note that any data you collect using BMS forms must not be publicly identified as BMS data. In any publications that merge BMS's data with non-BMS entity's data, acknowledgement of NIDILRR funding is not permitted except where those data collected by the BMS are clearly identified.

For any questions about the BMS data collection forms, the BMS public access dataset, or other enquiries, contact burndata@uw.edu.

