

# Burn Model System Summary Report

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*1994–2020*

This report contains information, tables, and figures about the data contained in the Burn Model System National Database, collected from 1993 to 2020. 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.



2021



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# Introduction

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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;
- University of Texas Medical Branch 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 Center.

The BMS NDSC supports the research teams in the clinical burn centers. It also manages data collected by the BMS centers on more than 6,600 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, 2020, the database contained information for 4,303 adults (18 years of age and older at the time of burn) and 2,325 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

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## 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 Galveston 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

# COVID-19 Impact on the Burn Model System

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Due to the nature of the BMS data collection (often done in-person at the hospital or at follow-up visits at burn clinics), the BMS has been affected by the COVID-19 global pandemic. In March 2020, all centers had to halt in person enrollment and data collection due to institutional restrictions on in-person research.

Throughout much of 2020, BMS data collectors worked from home and collected data from participants via phone interviews or through online surveys. Institutions began easing restrictions later in the year, but rules and processes varied by BMS Center and none of the centers returned to full operations by the end of 2020.

To remain responsive to institutional requirements and data collection restrictions, the BMS instituted an enrollment window hiatus policy on March 9<sup>th</sup>, 2020. Pre-pandemic participants had to be enrolled into the BMS within 30 days of hospital discharge, but because institutions across the country were restricting access to patients to ensure the safety of patients and reduce the spread of the virus, this requirement was removed during the pandemic and participants were allowed to be enrolled outside of 30 days after leaving the hospital. At the time of publishing this report (May 2021) this policy is still in place. Until the pandemic is over, potential participants can be approached for consent and enrollment into the BMS NLDB beyond 30 days after hospital discharge.

# Summary of Burn Model System Findings 1994–2020

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- 6,629 people consented to participate in the BMS database.
- 471 people died before hospital discharge.
- 1,096 people were eligible but did not agree to participate in the study.
- 71% of the participants in the database were male.
- 35% of the participants were younger than 18 years of age at the time of their burn injury.
- 72% of the participants were Caucasian; 17% were African-American; and 27% identified as Hispanic.<sup>1</sup>
- Mean TBSA burned was 24% across all participants.
- 47% of participants had at least 20% TBSA burned.
- Length of acute care hospital stay averaged 31 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 29 days for adults ages 75 years and older.
- From 1994 to 2020, 696 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 four 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.<sup>2</sup> The BMS plans to assess representativeness in another study in 2021.

## Cause of Injury<sup>3</sup>

- Fire/flare: 59%
- Scald: 16%
- Grease: 8%
- Electrical: 6%
- Contact with hot object: 5%
- Flash: 3%
- Chemical: 2%

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

<sup>2</sup> 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.

<sup>3</sup> 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 53% of all participants. Table 2 shows the breakdown of sex in the total sample.

Figure 1. Number of Participants by Sex and Age Group

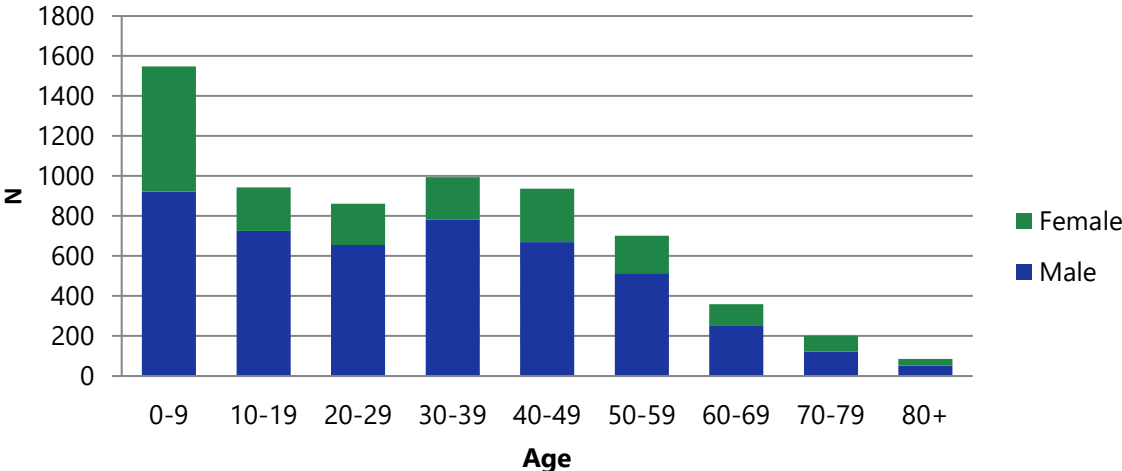


Table 1. Number and Percentage of Participants by Age Group

Age (Years)	Number of Participants	%
0-9	1,548	23.4
10-19	943	14.2
20-29	861	13.0
30-39	994	15.0
40-49	937	14.1
50-59	701	10.6
60-69	359	5.4
70-79	200	3.0
80+	86	1.3
<b>Total</b>	<b>6,629</b>	

Table 2. Number and Percentage of Participants by Sex

Sex	Number of Participants	%
Male	4,696	70.8
Female	1,933	29.2
<b>Total</b>	<b>6,629</b>	

## 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

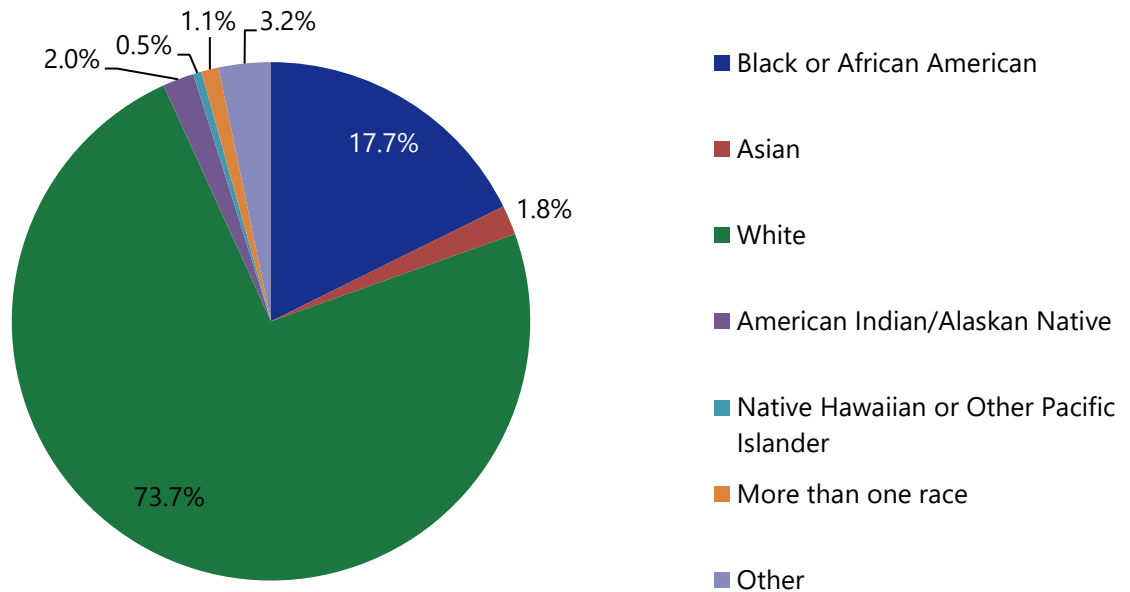


Table 3. Number and Percentage of Participants by Ethnicity

Ethnicity	Number of Participants	%
Hispanic or Latino	1,770	26.7
Not Hispanic or Latino	4,543	68.5
Missing/unknown	316	4.8
<b>Total</b>	<b>6,629</b>	

## 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	5,921	89.3
Homeless	69	1.0
Missing/unknown	639	9.6
Total	6,629	

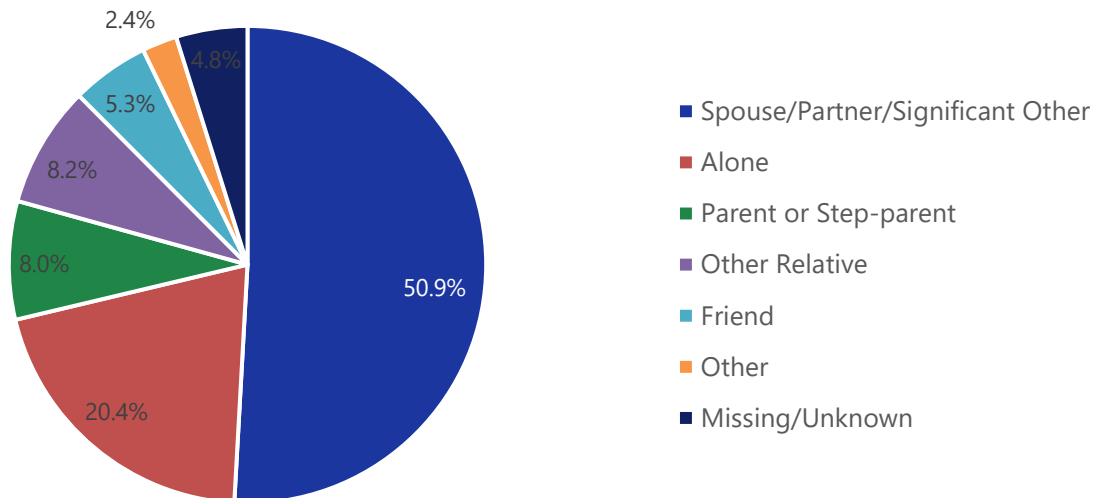
Figure 3. Geographical Location of Residence at Time of Burn Injury



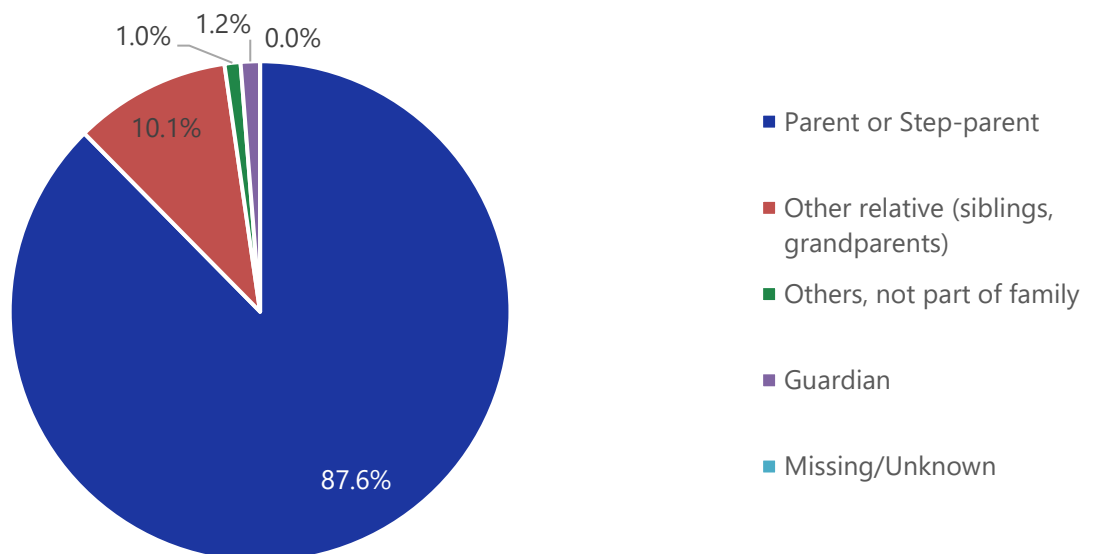
## Living Situation at Time of Injury

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 ( $n = 4,304$ ). 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 ( $n = 1,250$ ). 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	2,658	61.8
Not employed	1,019	23.7
Retired	432	10.0
Homemaker/caregiver	54	1.3
Volunteer	8	0.2
Missing/unknown	133	3.1
<b>Total</b>	<b>4,304</b>	

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

School Status	Number of Participants	%
In school	936	74.9
Not in school	170	13.6
Missing/unknown	166	13.1
<b>Total</b>	<b>1,250</b>	

## Adults Reporting Pre-Injury Alcohol Use and Drug Use

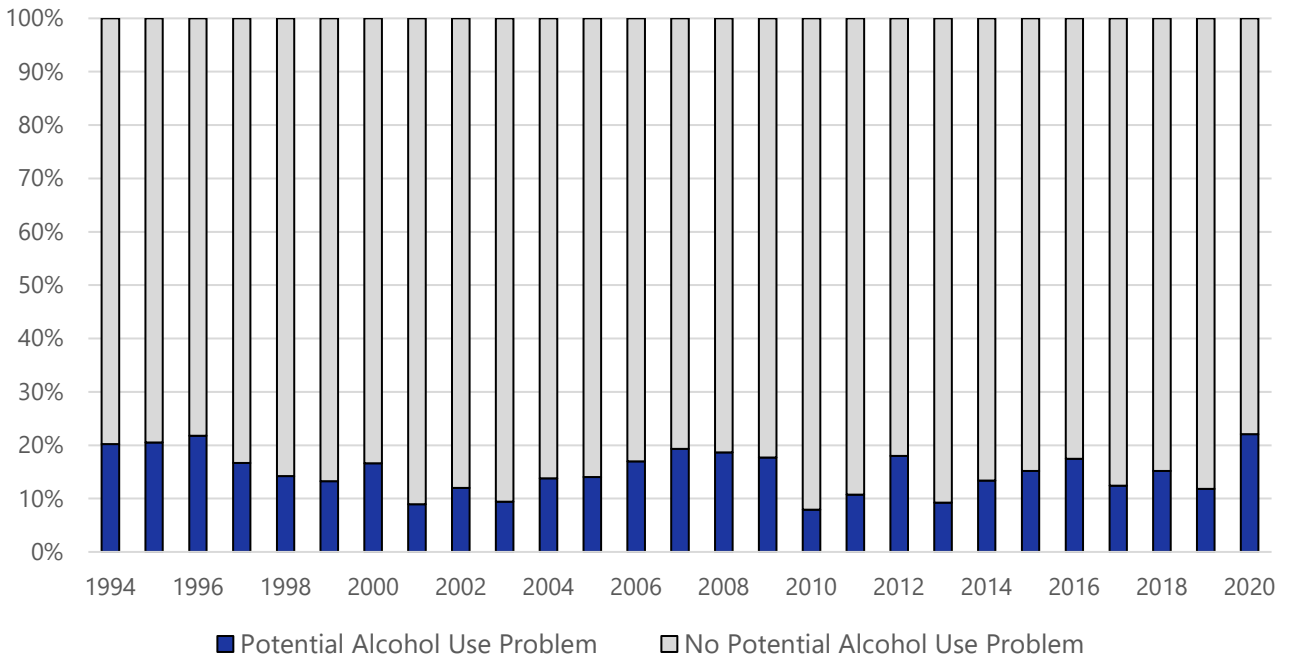
Table 7 lists pre-injury alcohol and drug use for adults as measured by the CAGE. The CAGE is a commonly used assessment for alcohol problems. The name comes from an acronym of the four questions in the measure. The amount of missing data varies for each of these variables but is approximately 8.3% for each. Figure 6 and 7 show the % of those with a possible alcohol use and drug problems by burn year.

Table 7. Pre-Injury Alcohol and Drug Use

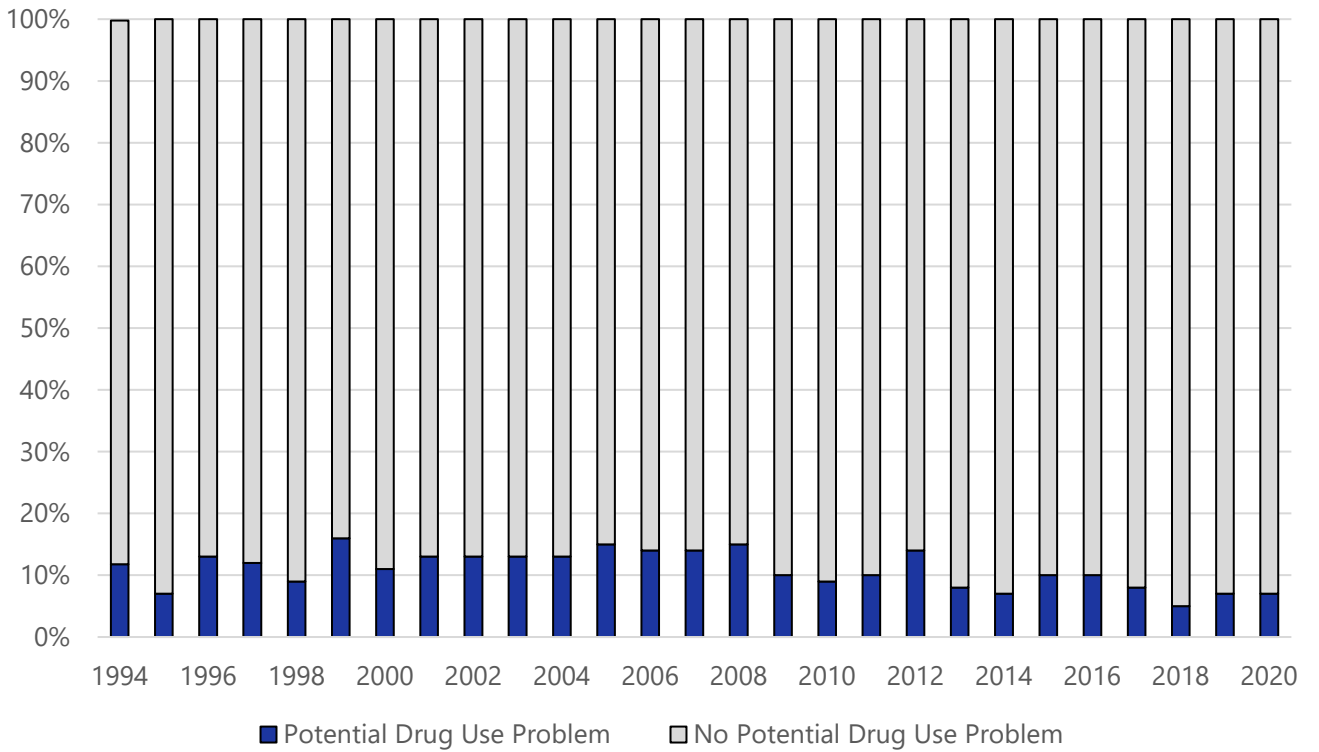
Pre-Injury Alcohol and Drug Use	Number of Participants	%
Alcohol use indicating a potential problem in past 12 months	592	13.8%
Drug use indicating a potential problem in past 12 months	437	10.2%



**Figure 6. Percentage of People Indicating Potential Alcohol Use Problem By Burn Year**



**Figure 7. Percentage of People Indicating Potential Drug Use Problem By Burn Year**



## Adults 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 adults 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 (14.7% 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	123	18.0

## Adults Reporting Incarceration

Table 9 identifies the prevalence of incarceration before the burn injury among adults 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 (22.7% 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	53	8.6

# Characteristics of Burn Injury

## Total Body Surface Area Burned

Figure 8 shows the number of participants in the BMS database by burn size. Among database records that reported burn size, 52.6% 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 (0.7%) participants had burn size that was unknown or not recorded.

Figure 8. Number of Participants by Burn Size Category (% TBSA Burned)

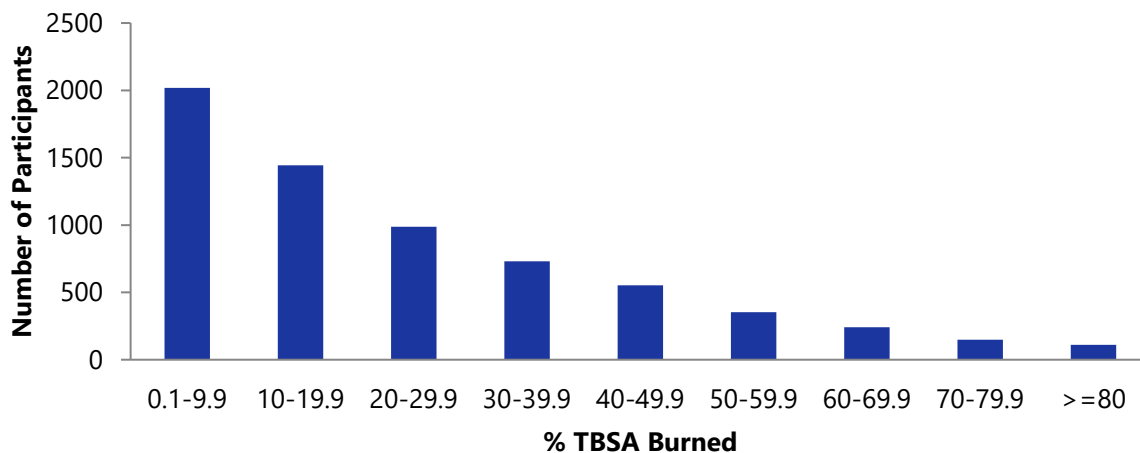


Table 10. Number and Percentage of Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Number of Participants	%
0.1-9.9	2,018	30.7
10-19.9	1,444	21.9
20-29.9	987	15.0
30-39.9	731	11.1
40-49.9	552	8.4
50-59.9	353	5.4
60-69.9	240	3.6
70-79.9	148	2.2
>=80	111	1.7
Missing/unknown	45	0.7
<b>Total</b>	<b>6,629</b>	

## 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	%	No	%	Missing/Unknown	%
Head/neck burn	3,654	55.1	2,903	43.8	72	1.1
Trunk burn	4,126	62.2	2,442	36.8	61	0.9
Perineum burn*	1,095	16.5	4,992	75.3	542	8.2
Arm burn (right, left, or bilateral)	4,685	70.7	1,930	29.1	14	0.2
Hand burn (right, left, or bilateral)	4,396	66.3	2,157	32.5	76	1.2
Leg burn (right, left, or bilateral)	3,907	58.9	2,659	40.1	63	1.0
Foot burn (right, left, or bilateral)	2,143	32.3	4,396	66.3	90	1.4

\*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	%	No	%	Missing/Unknown	%
Head/neck burn	1,224	18.5	5,241	79.1	164	2.5
Trunk burn	2,578	38.9	3,901	58.9	150	2.3
Perineum burn*	520	7.8	5,357	80.8	752	11.3
Arm burn (right, left, or bilateral)	3,420	51.6	3,132	47.2	77	1.2
Hand burn (right, left, or bilateral)	2,853	43.0	3,609	54.4	167	2.5
Leg burn (right, left, or bilateral)	2,909	43.9	3,576	53.9	144	2.2
Foot burn (right, left, or bilateral)	1,504	22.7	4,947	74.6	178	2.7

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

## Cause of Injury

Figure 9 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 1.8% 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 10 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 9. Distribution of Participants by Cause of Injury

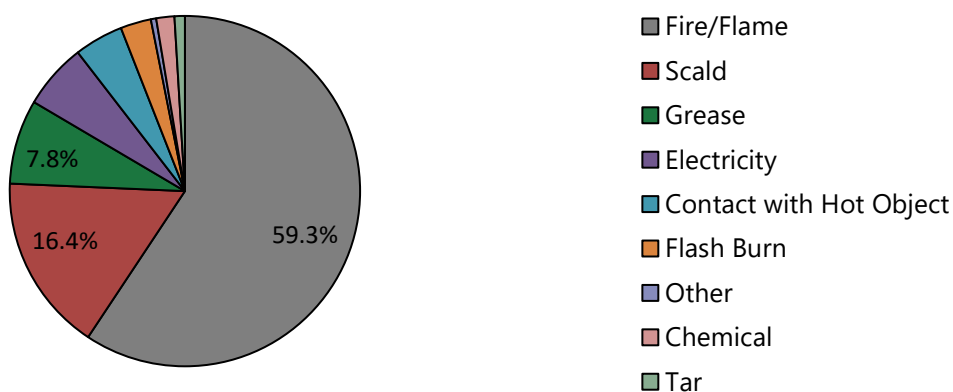
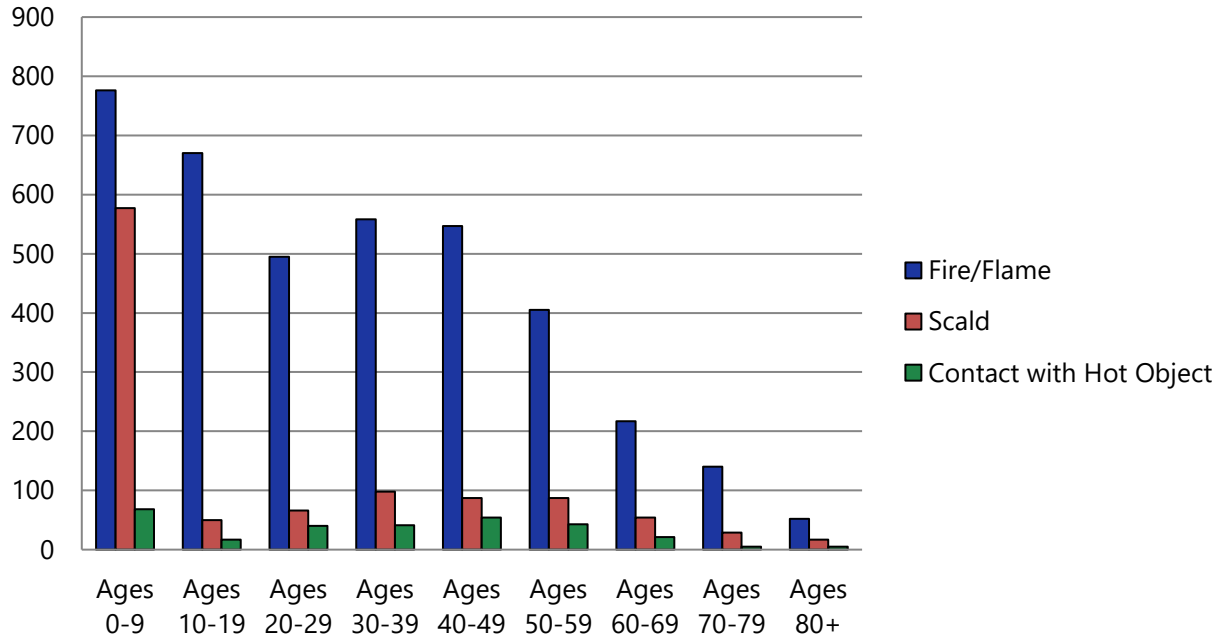


Table 13. Number and Percentage of Participants by Cause of Injury

Cause of Injury	Number of Participants	%
Fire/Flame	3,860	58.2
Scald	1,065	16.1
Grease	507	7.7
Electricity	394	5.9
Contact with Hot Object	294	4.4
Flash Burn	184	2.8
Chemical	109	1.6
Tar	62	1.6
Other	32	0.5
Unknown/Missing	122	1.8
<b>Total</b>	<b>6,629</b>	

Figure 10. Number of Participants by Cause of Injury and Age Group



## Circumstances and Place of Injury

Table 14 and Figure 11 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, 16.3% 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 12 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	3,408	51.4
Non-intentional employment related	1,055	15.9
Non-intentional recreation	891	13.4
Non-intentional unspecified	736	11.1
Suspected self-inflicted/suicide	150	2.3
Suspected assault--domestic	143	2.2
Suspected assault--non-domestic	85	1.3
Suspected arson	21	0.3
Missing/unknown	140	2.1
<b>Total</b>	<b>6,629</b>	

**Figure 11. Distribution of Participants by Circumstance of Injury**

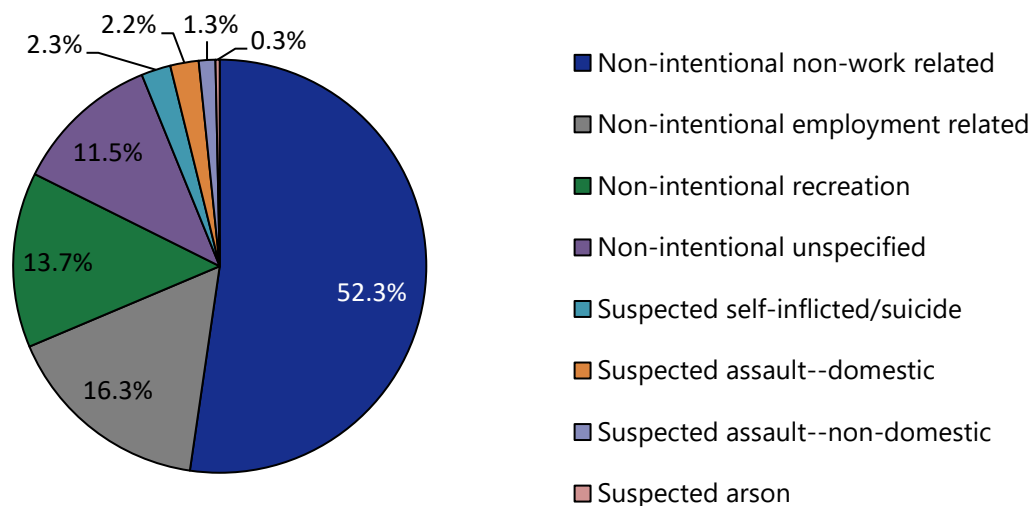
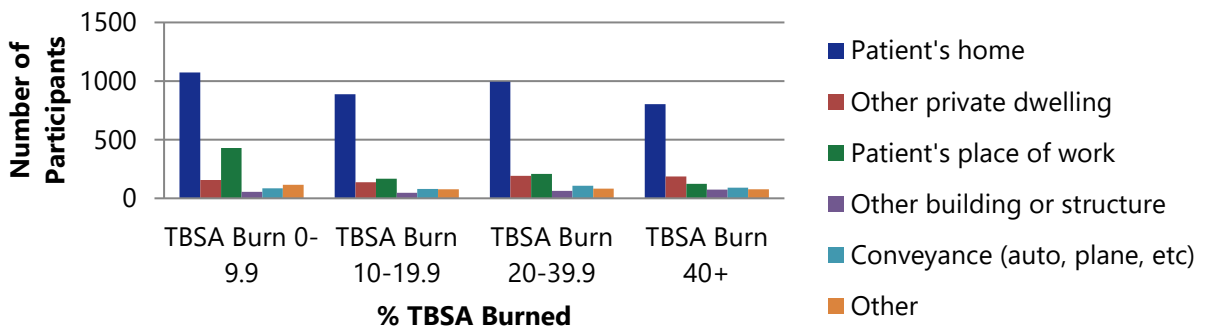


Table 15. Number and Percentage of Participants by Place of Injury

Place of Injury	Number of Participants	%
Closed/Indoors	3,879	59.4
Open/outdoors	2,553	39.1
Missing/unknown	197	3.0
<b>Total</b>	<b>6,629</b>	

Figure 12. 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	1,005	15.5
Other injury	809	12.5
Range of motion deficit	3,185	54.7

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

Gender	Inhalation Injury %	Other Injuries%
Males	14.8	13.0
Females	17.1	11.4



# Treatment Before Discharge

## Length of Acute Care Hospital Stay

Figure 13 shows the average length of acute care hospital stay at the BMS Center per year among participants in the BMS database. Only 18 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 2020, the average length of stay was 29 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 13. Average Length of Acute Care Hospital Stay Among Participants by Year (1993–2020)

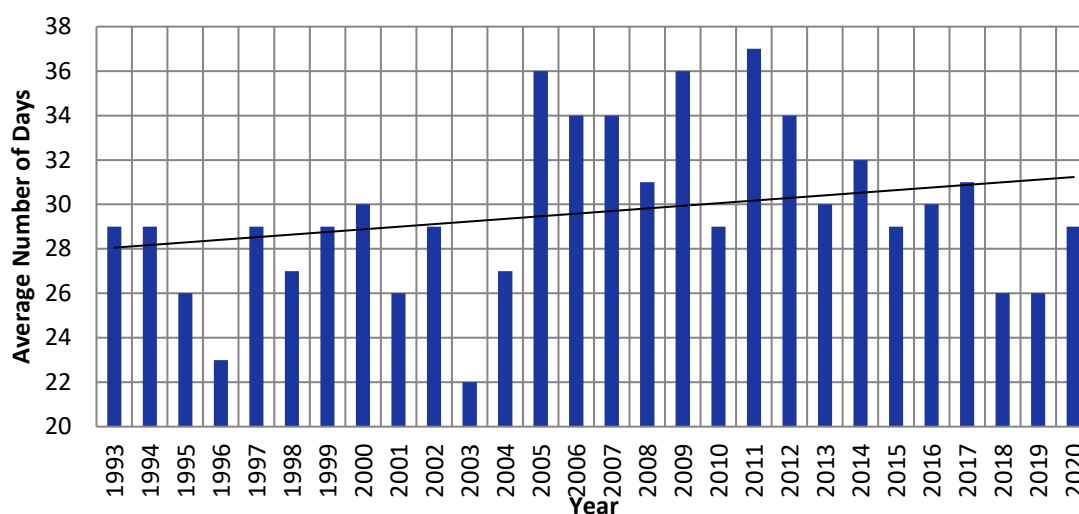


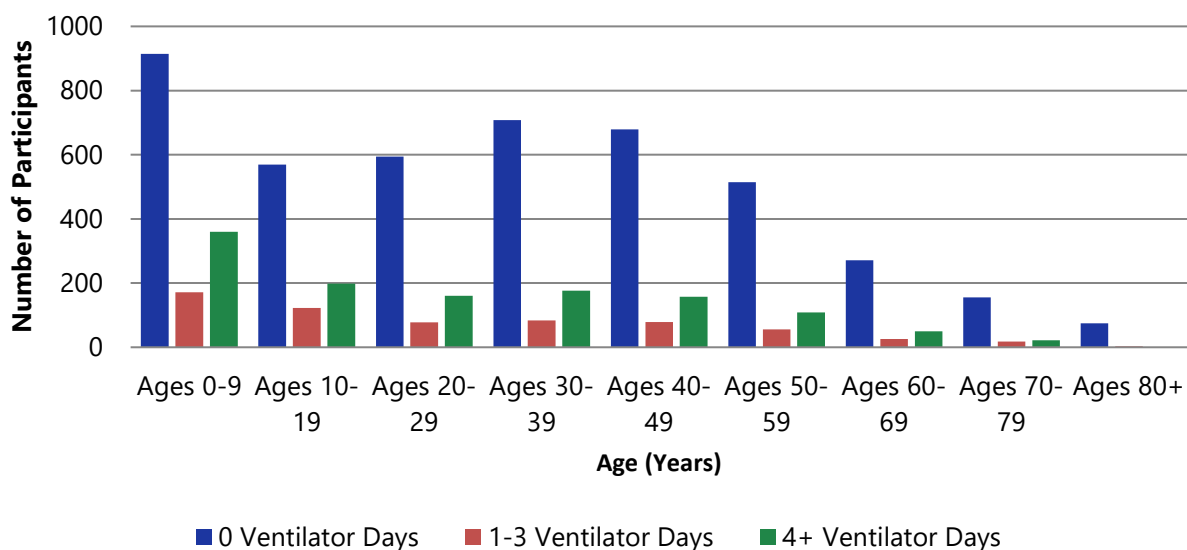
Table 18. Average Length of Acute Care Hospital Stay Among Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Average Length of Hospital Stay (Days)
0–9.9	16.2
10–19.9	20.3
20–29.9	27.9999
30–39.9	34.5
40–49.9	42.2
50–59.9	45.4
60–69.9	56.9
70–79.9	72
≥80	111.1

## Ventilator Days

Figure 14 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 14 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 14. 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)	4,569	86.3
1–10 days of rehab	173	3.3
11–20 days of rehab	244	4.6
≥21 days of rehab	300	5.7
Missing/unknown	9	0.2
<b>Total</b>	<b>5,295</b>	

\*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 15 shows the distribution of participants in the BMS database by type of disposition at hospital discharge. Figure 15 is based on available data. Table 20 identifies the number and percentage of each type of disposition for the sample.

Figure 15. Distribution of Participants by Type of Disposition at Hospital Discharge

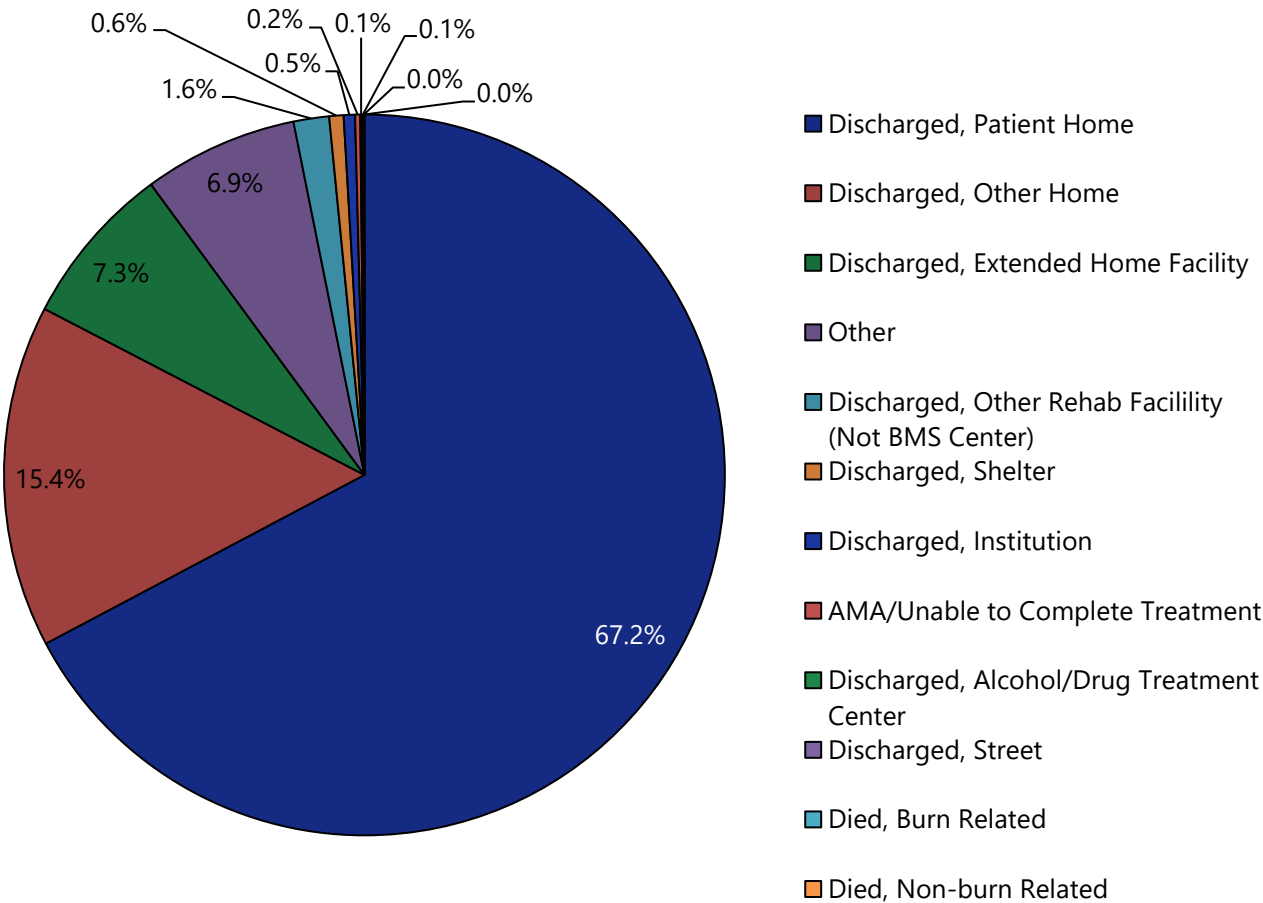


Table 20. Number and Percentage of Participants by Type of Disposition at Hospital Discharge

Disposition	Number of Participants	%
Discharged, patient home	4,388	66.2
Discharged, other home	1,003	15.1
Discharged, extended home facility	476	7.2
Other	452	6.8
Discharged, other rehab facility (not BMS Center)	104	1.6
Discharged, shelter	42	0.6
Discharged, institution	33	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	104	1.6
<b>Total</b>	<b>6,629</b>	

## 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	1,556	23.5
Philanthropy; private support	1,074	16.2
Medicaid	956	14.4
Worker's compensation	684	10.3
Medicare	564	8.5
Self-pay (public support)	532	8.0
Other	529	8.0
Champus/Tri-Care	29	0.4
VA	27	0.4
Missing/Unknown	678	10.2
<b>Total</b>	<b>6,629</b>	

# 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 2018). Figure 16 shows a graph of the number of people eligible and then the number of people enrolled. Figure 17 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 18 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	Hospital Discharge	6 Months		12 Months		24 Months	
		Number of Participants	%	Number of Participants	%	Number of Participants	%
Total number eligible:	8,374						
Total number enrolled:	6,629						
Data collected/Follow-up Complete		4,784	76.6	4,238	76.3	3,596	68.1
Death due to burn-related complications		27	0.4	23	0.4	21	0.4
Death due to non-burn complications		26	0.4	51	0.9	72	1.4
Unable to locate		401	6.4	455	8.1	703	13.3
Refused this assessment		58	0.9	49	0.9	89	1.7
Unable to test/medically incapable of responding		17	0.3	23	0.4	32	0.6
Failed to respond		832	13.3	671	11.9	642	12.2
Did not consent to future assessment/withdrew		69	1.1	83	1.5	88	1.7
Incarcerated		7	0.1	23	0.4	26	0.5
Still in hospital (not discharged yet)		12	0.2	13	0.2	7	0.1
Other		11	0.2	1	0.02	1	0.02

Figure 16. Number of People Eligible for the BMS study and Number of People Enrolled by Year

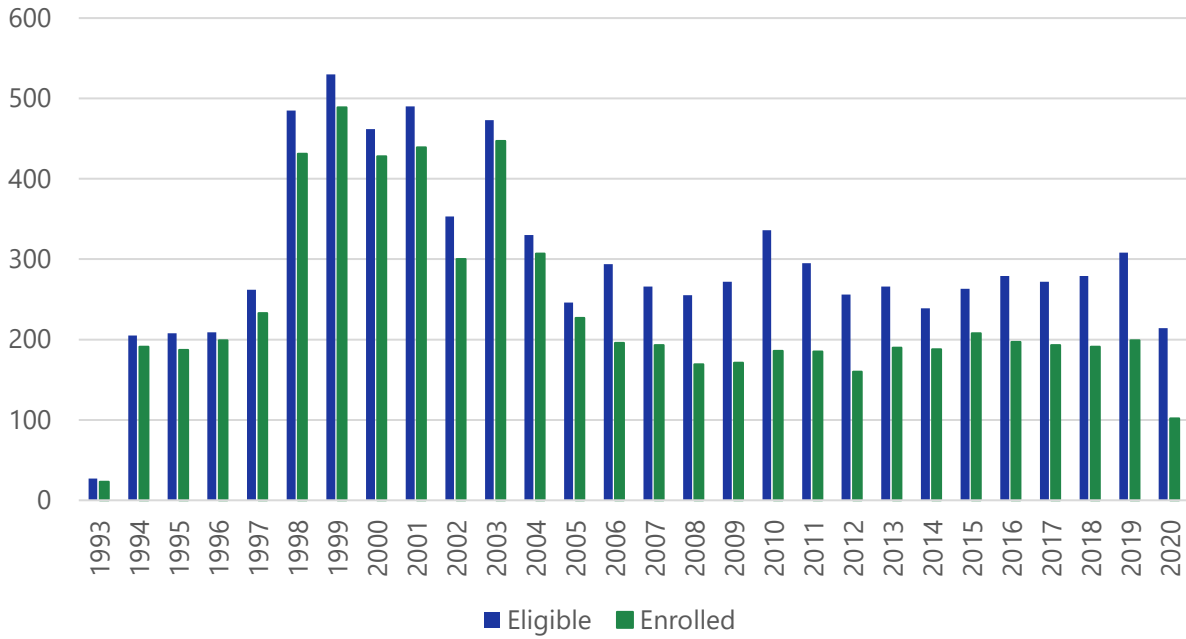


Figure 17. Number of Participants With Data at Long-Term Follow-Ups

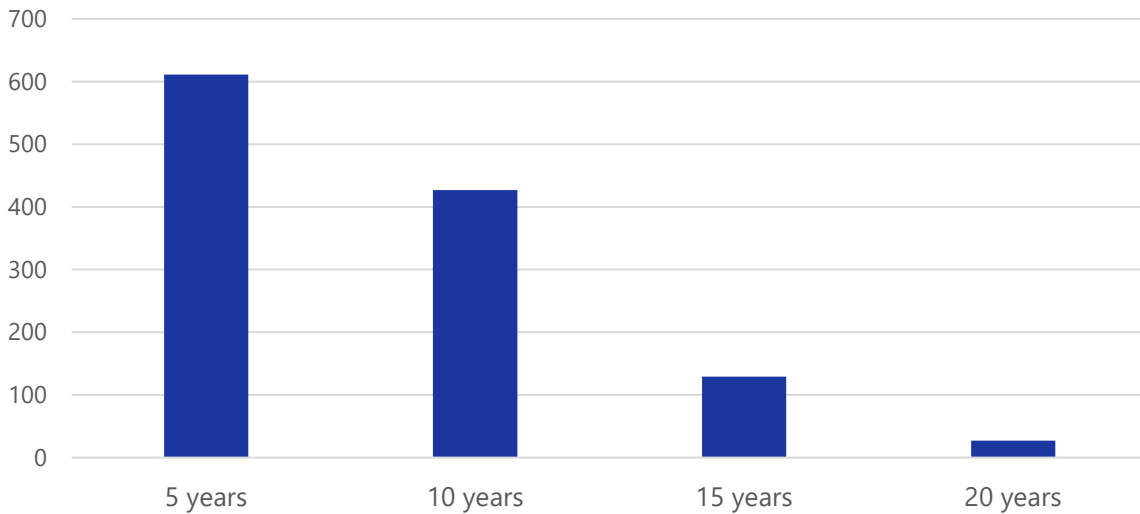
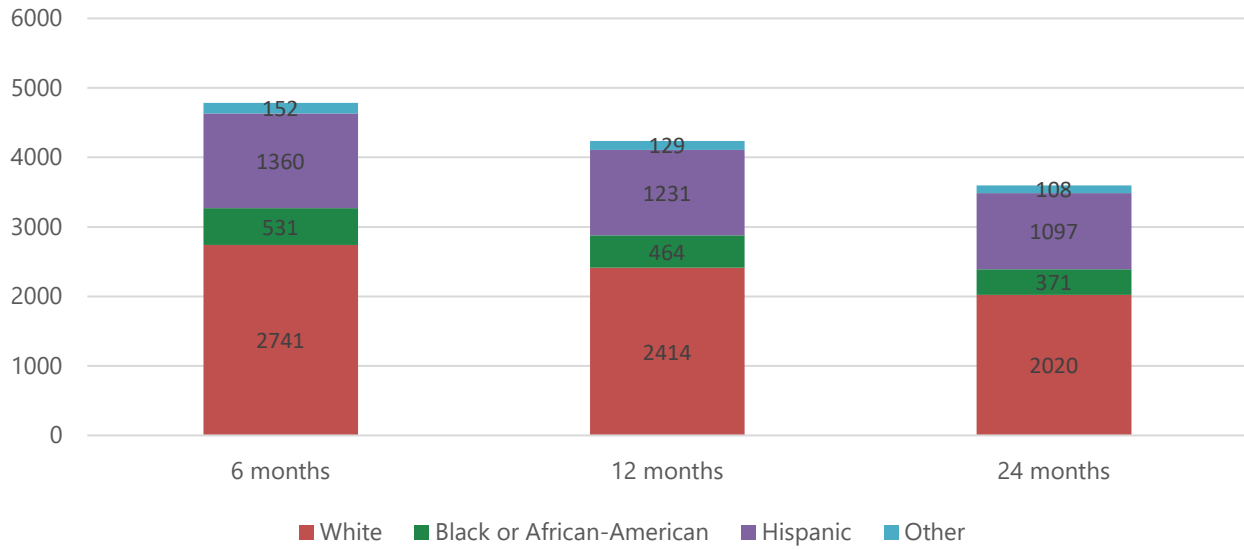


Figure 18. Follow-Ups Completed by Racial/Ethnic Group





# 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	81	15.9	64	14.3	72	17.9	24	17.0
Change in voice	62	12.2	48	10.6	44	10.9	20	13.9
Vision problems not corrected by contacts or glasses	70	13.7	53	11.6	40	9.9	22	15.4
Eyelid problems	32	6.3	23	5.0	23	5.7	9	6.3
Excessive tearing of the eyes	46	9.1	54	11.8	41	10.2	14	9.7
Difficulty with memory	140	27.6	125	27.6	117	29.3	48	33.8
Difficulty with thought processing	113	22.1	97	21.3	99	24.9	34	23.6
Numbness, pins and needles or burning sensations in burn scar	349	67.4	284	61.2	206	50.5	77	53.5
Numbness, pins and needles or burning sensations in hands	239	46.8	182	39.7	138	34.0	57	39.3
Numbness, pins and needles or burning sensations in feet	150	29.5	126	27.7	104	25.6	40	27.8
Trouble with balance	144	28.0	115	25.3	109	27.1	47	32.4
Varicose veins	57	11.4	53	11.9	49	12.4	15	10.5
Swollen feet or legs	128	25.1	95	21.0	85	20.9	37	25.3
Swollen hands or arms	73	14.5	40	8.8	40	9.8	10	6.9
Difficulty with breathing when doing regular activities	95	18.6	90	19.7	76	18.8	24	16.4
Skin cancer	10	2.04%	121	2.7	10	0.9%	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	
	N	%	N	%	N	%	N	%
Seeing	13	6.3	17	8.5	17	8.9	23	21.5
Hearing	4	1.9	3	1.5	10	5.2	8	7.5
Learning and understanding	18	8.8	19	9.5	35	18.2	26	24.5
Controlling emotions or behavior	73	35.6	54	27.3	62	32.3	39	36.5
Sleeping	12	5.9	12	6.0	5	2.6	11	10.3
Breathing	18	8.8	11	5.5	11	5.8	8	7.5
Chronic open skin areas	36	17.5	33	16.3	22	11.4	9	8.4
Other skin problems	22	10.8	16	8.0	21	11.0	8	7.5

## Physical and Mental Health Outcomes among Adults

Table 27 presents data on the physical function, sleep, anxiety, depression, pain interference and fatigue scores among adult participants in the BMS database at four time-points. These problems are assessed using the PROMIS-29 profile<sup>4</sup>, 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. Scores reflect higher levels of what is being measured; thus, higher physical function scores mean better function, while higher sleep disturbance and fatigue scores mean more sleep disturbance and fatigue. 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 19 shows mean physical function, sleep, anxiety, depression, pain interference and fatigue scores by cross-sectional time point. These are trends in the data as a whole and do not necessarily represent individual participant experience or repeated measures.

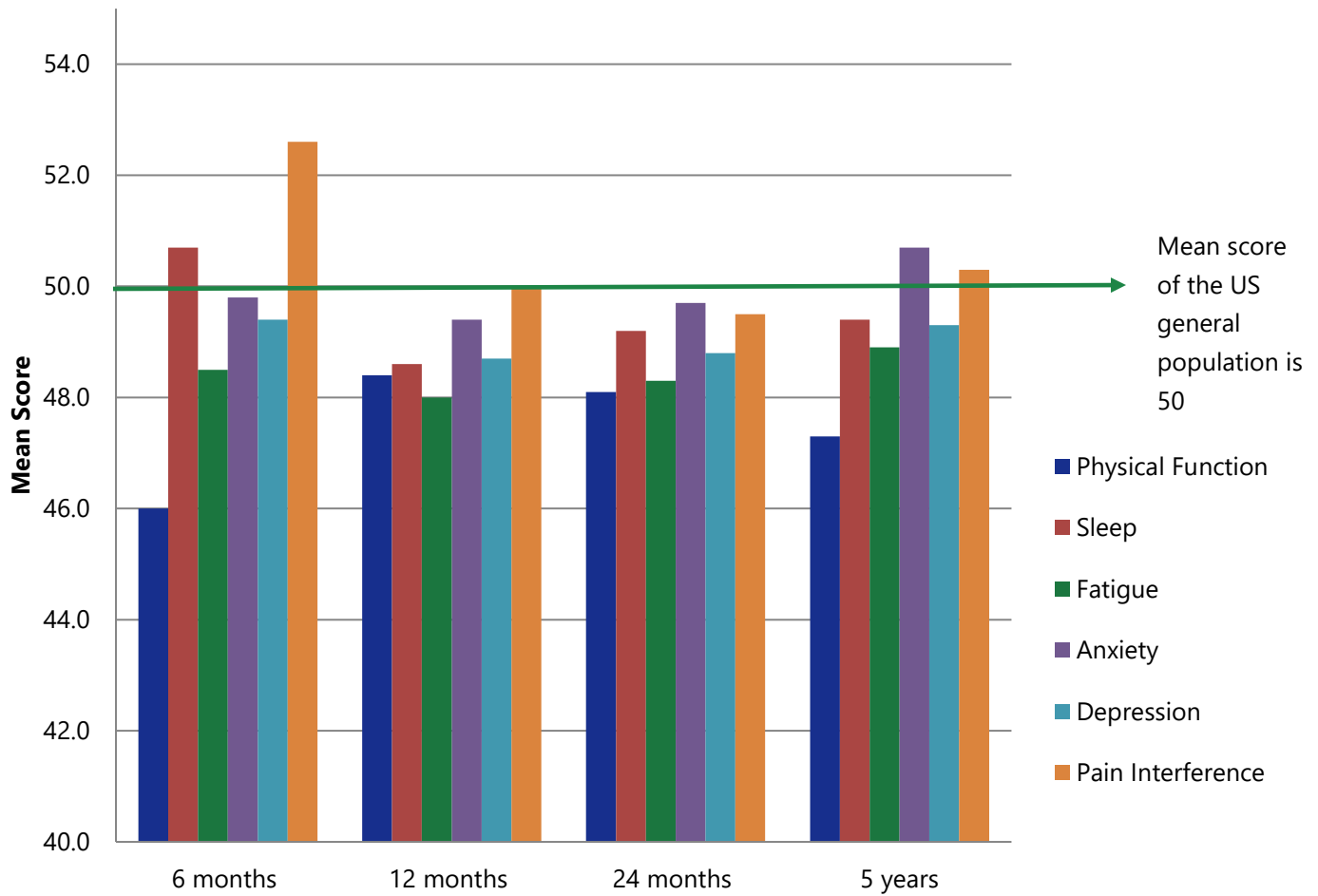
**Table 27. Mean Outcome Scores by Time-Point for Adult BMS Participants\***

	6 Months		12 Months		24 Months		5 years	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Physical Function	46.0 (10.0)	485	48.4 (9.7)	447	48.1 (9.7)	403	47.3 (9.7)	143
Sleep Disturbance	50.7 (10.5)	493	48.6 (10.5)	450	49.2 (11.1)	404	49.4 (10.0)	146
Fatigue	48.5 (11.7)	489	48.0 (11.6)	447	48.3 (11.8)	394	48.9 (11.4)	145
Anxiety	49.8 (10.0)	488	49.4 (10.1)	450	49.7 (10.4)	401	50.7 (11.2)	146
Depression	49.4 (9.8)	487	48.7 (9.9)	447	48.8 (9.9)	398	49.3 (9.8)	146
Pain interference	52.6 (10.5)	489	50.0 (10.1)	449	49.5 (10.1)	399	50.3 (10.0)	144

\*Data collected since 2015

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

Figure 19. Mean Outcome Scores by Time-point for Adult BMS Participants



# Functional Outcomes After Burn Injury

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

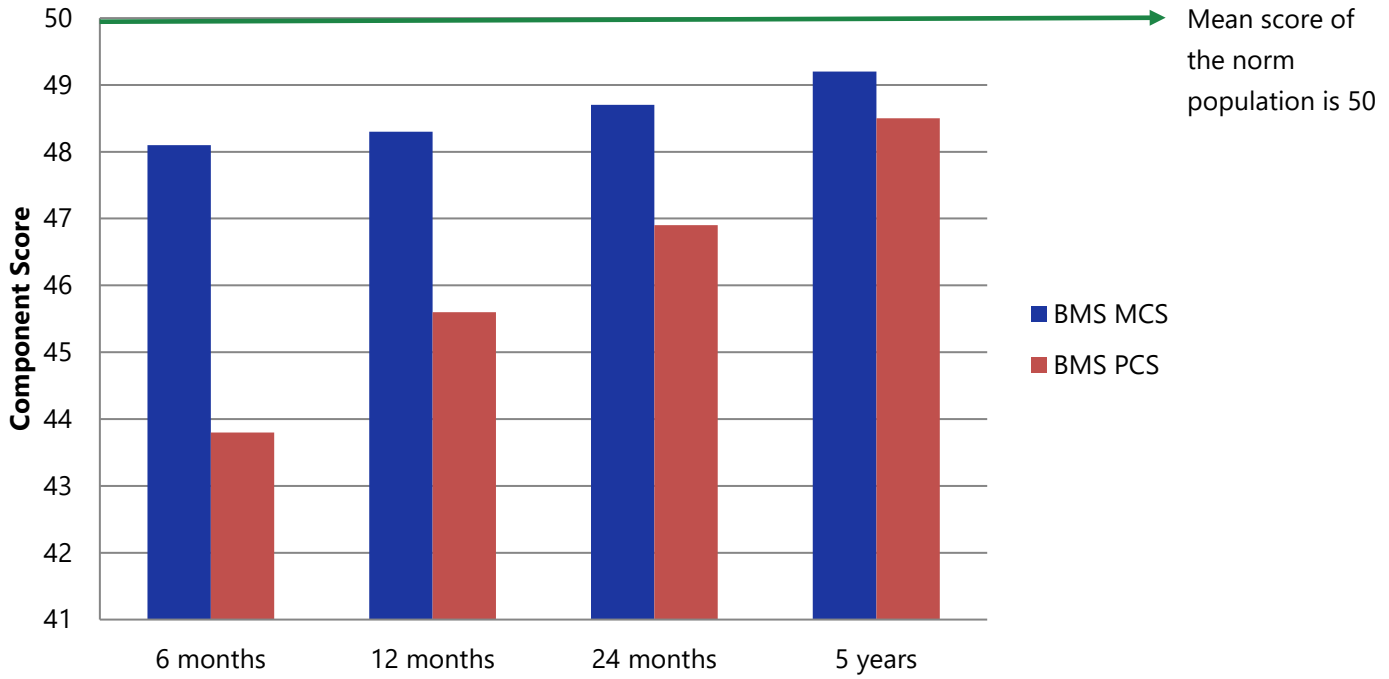
Table 28 presents the mean VR12/SF-12 Mental Health Component (MCS) and Physical Health Component (PCS) scores for adult participants, in the BMS database at each follow-up time-point. The SF12/VR-12 are sets of questions that clinicians ask patients to understand how people are doing physically and 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, with the VR-12 scores cross-walked to the SF-12 metric. 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	6 Months		12 Months		24 Months		5 Years	
	Mean	N	Mean	N	Mean	N	Mean	N
MCS	48.1	1,863	48.3	1,729	48.7	1,506	49.2	369
PCS	43.8	1,863	45.6	1,729	46.9	1,506	48.5	369

\*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 20. 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 ( $n = 4,304$ ), 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 ( $n = 1,250$ ). 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	1,235	35.4	1,275	41.3	1,180	45.0
Not Working	1,883	53.9	1,466	47.4	1,141	43.6
Homemaker/Caregiver	37	1.1	39	1.3	33	1.3
Volunteer	18	0.5	9	0.3	12	0.5
Retired	318	9.1	301	9.7	254	9.7

\*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	602	17.5	502	76.0	439	72.8
Not school	128	82.5	159	24.1	164	27.2

\*Data collection for these variables began in 2009.

# Burn Model System Data Collection Additions

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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
<b>Domain: Demographics (including income, marital status, living situation, work status, school status, etc.)</b>					
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
<b>Domain: Burn Injury Information</b>					
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
<b>Domain: Medical Conditions</b>					
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
<b>Domain: Health Related Quality of Life</b>					
Veteran's Rand 12	Pre-burn (administered at discharge), and all follow-ups	New (replaces the SF12)	Ages ≥18	Standardized	12
<b>Domain: Global Health (including depression, fatigue, anxiety, peer relationships, anger)</b>					
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
<b>Domain: Community Participation</b>					
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
<b>Domain: Depression</b>					
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
<b>Domain: Anger</b>					
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
<b>Domain: Stigma/Body Image</b>					
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
<b>Domain: Itch</b>					
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
<b>Domain: Posttraumatic Stress Disorder</b>					
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

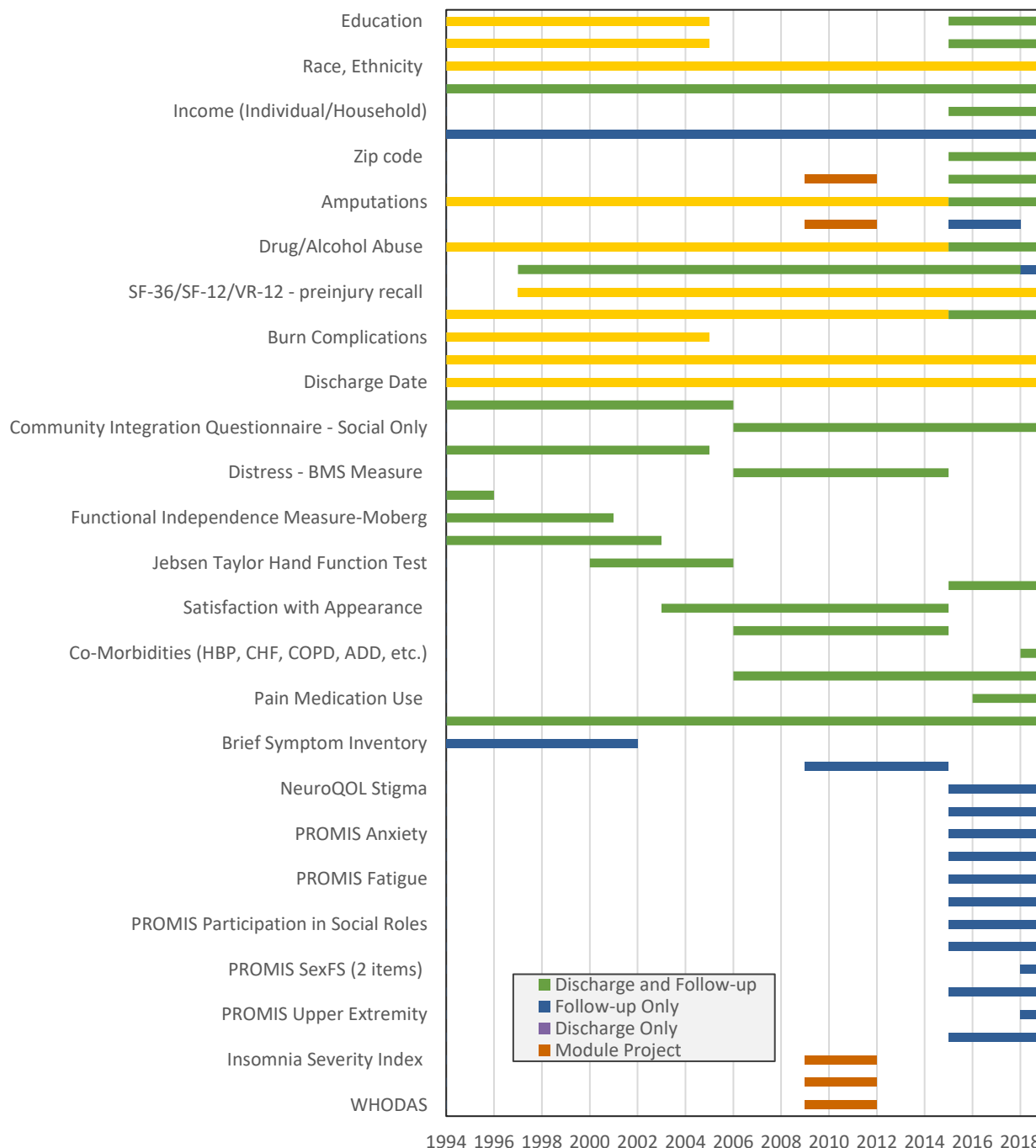
Measure	Time-Point Administered	New, Dropped, or Previously Administered?	Age Group (Years) Administered To	BMS or Standardized Measure?	Number of Items in Measure
<b>Domain: Drug/Alcohol/Medication Use</b>					
CAGE Alcohol/Drug Use	Discharge and all follow-ups	Previously administered at discharge; 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
<b>Domain: Posttraumatic Growth</b>					
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
<b>Domain: Physical Function</b>					
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
<b>Domain: Satisfaction With Life/Positive Affect</b>					
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

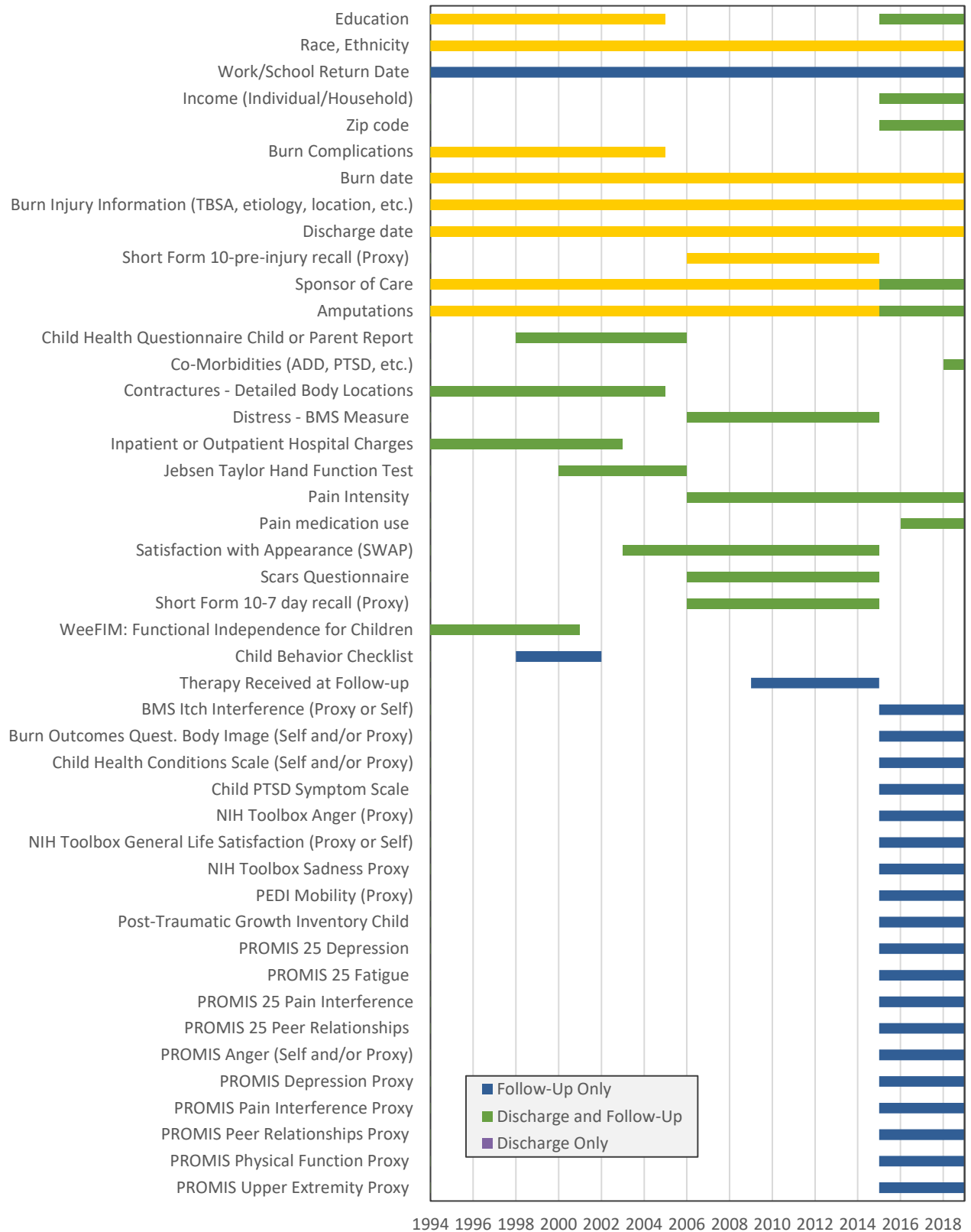
# Archived Burn Model System Data

The Burn Model System has collected many other measures in addition to those represented in this report since 1993. Figure 21 and Figure 22 represent what data have been collected, and when, for adults and pediatrics, respectively.

**Figure 21. Timeline of Burn Model System Variable and Measure Administration, Adults**



**Figure 22. 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](mailto: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](mailto: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

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## 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

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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 injury<sup>5</sup>.
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

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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)

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

4. VR-12: [https://www.rand.org/pubs/research\\_reports/RR1844.html](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**

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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](mailto:burndata@uw.edu).**

