Burn Model System Summary Report

1994–2023

This report contains information, tables, and figures about the data contained in the Burn Model System National Database, collected from 1994 to 2023. 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.

BMS
National Data &
Statistical Center

BURN MODEL SYSTEM
BMS
ADVANCING RECOVERY THROUGH KNOWLEDGE

2024

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Introduction

Severe burns are one of the most complex forms of traumatic injury. People with burn injuries often require long-term rehabilitation. Survivors of a burn injury often have a wide range of physical and psychosocial problems that can affect their quality of life. The Burn Model System (BMS) program began in 1994, with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), 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:

- Boston-Harvard Burn Injury Model System (BH-BIMS) in Boston, Massachusetts
- North Texas Burn Rehabilitation Model System (NTBRMS) in Dallas, Texas
- Northwest Regional Burn Model System (NWRBMS) in Seattle, Washington; and
- Southern California Burn Model System (SCBMS) in Los Angeles, California

Past centers include the University of Texas Medical Branch Burn Injury Rehabilitation Model System in Galveston, Texas, the Johns Hopkins University Burn Model System in Baltimore, Maryland, the University of Colorado Denver National Data and Statistical Center, and the 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 7,000 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, 2023, the database contained information for 4,913 adults (18 years of age and older at the time of burn) and 2,402 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 (BH-BIMS)

The BH-BIMS 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, 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 conduct a randomized controlled trial (RCT) using the Stanford Chronic Disease Self-Management Program to provide persons living with burn injury the skills to navigate their recovery and long-term outcomes. Newly generated data from the RCT will further enhance research and models of care for burn injury survivors.

Project Director:
Jeffrey Schneider, MD

Project Manager:
Lauren Shepler, 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 2,500 participants since the BMS began. During the 2022-2027 funding cycle, the NTBRMS has a site-specific research study that examines the overall efficacy of A Social Interaction Skills Training (ASIST) intervention in facilitating community participation and social integration among adult burn survivor participants. The study will also examine the efficacy of the ASIST intervention between racial and ethnic minority participants and their White counterparts. This study's overall aim is to enhance long-term rehabilitation outcomes, especially among community reintegration trajectories, in burn injury survivors by establishing ASIST programming as standard of care within burn centers.

Project Director:
Karen Kowalske, MD

Project Manager:
Kyra Solis-Beach, BS, CHES

Southern California Burn Model System (SCBMS)

The SCBMS is centered in the University of Southern California at the Los Angeles County/University of Southern California Medical Center. The SCBMS serves the greater Los Angeles area, which is one of the most diverse economic and ethnic populations in the country. In addition to contributing to the national database, the SCBMS site-specific project will focus on the effectiveness of laser therapy for thick burn scars and how this helps in recovery. Another main project of the center is to create better systems of communication with people with burn injuries. The SCBMS works closely with the Wellness Center, a group of local community organizations, and the Southern California Clinical and Translational Science Institute, to help ensure that we create more culturally competent care for all patients. Through another collaboration with the Creative Media and Behavioral Health Center, a research unit of the Keck School of Medicine and the School of Cinematic Arts of USC, then center will find new forms of media and interactive games to help communicate and disseminate research findings.

Project Director:
Haig Yenikomshian, MD

Project Managers:
Elizabeth Flores
Elizabeth Mojarro-Huang

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. Additionally, the NWRBMS is working with people experiencing homelessness and King County homeless advocates, medical providers, case managers and outreach workers to understand how disabilities impact the lives of people who are experiencing homelessness and to define and implement improved strategies for engagement in longitudinal research and rehabilitation services.

Project Director:
Barclay Stewart, MD, PhD, MPH

Project Managers:
Gretchen Carrougher, RN, MN
Caitlin Orton, MPH

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 1994–2023

- 7,315 people consented to participate in the BMS database.
- 562 people died before hospital discharge.
- 2,354 people were eligible but did not agree to participate in the study.
- 71% of the participants in the database were male.
- 33% of the participants were younger than 18 years of age at the time of their burn injury.
- 73% of the participants were Caucasian; 17% were African-American; and 28% identified as Hispanic.[1]
- Mean TBSA burned was 23% across all participants.
- 45% of participants had at least 20% TBSA burned.
- Length of acute care hospital stay averaged 25 days for participants younger than 18 years of age.
- Length of stay averaged 27 days for adults ages 18–30 years, 25 days for adults ages 31–45 years; 26 days for adults ages 46–64 years; 24 days for adults ages 65–74 years; and 23 days for adults ages 75 years and older.
- From 1994 to 2023, 811 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 23 days.
- 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]

Cause of Injury[3]

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

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

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

[3] Percentages reported reflect those participants in the database with a known etiology (unknown cause of injury was excluded from this summary). Two percent of participants had "unknown" etiology (*n* = 129).

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 35% of all participants. The percentage of burn survivors is greatest among 20- to 60-year-olds, accounting for 54% of all participants. Table 2 shows the breakdown of sex in the total sample.

Figure 1. Number of Participants by Sex and Age Group

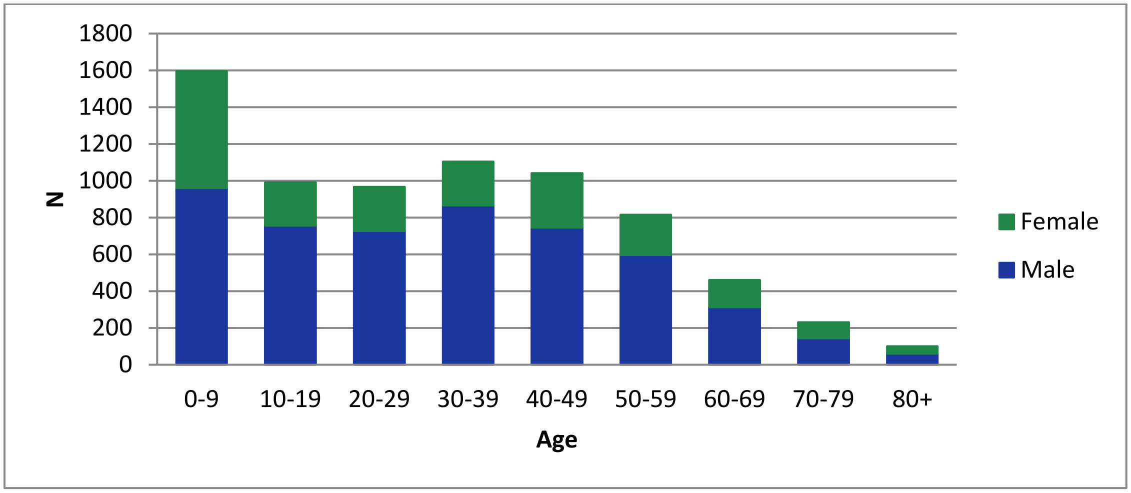


Table 1. Number and Percentage of Participants by Age Group

Age (Years)	Number of Participants	%
0-9	1577	21.6
10-19	967	13.2
20-29	924	12.6
30-39	1,066	14.6
40-49	1,003	13.7
50-59	764	10.4
60-69	414	5.7
70-79	221	3.0
80+	96	1.3
Missing/unknown	5	0.07
Total	7,315	

Table 2. Number and Percentage of Participants by Sex

Sex	Number of Participants	%
Male	5,172	70.7
Female	2,141	29.3
Missing/unknown	2	0.02
Total	7,315	

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 adult burn survivors in the BMS database by race and ethnicity. Figure 3 and Table 4 show the percentage and number of pediatric 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. Both Table 3 and 4 show the number of unknown or missing data. Figure 2 and Figure 3 are based on the records in which race was specified. The pediatric population is predominately Hispanic because the site that contributed many of the pediatric cases, the Pediatric Burn Model System Center in Galveston, Texas, had a large portion of their patient population come from Mexico or Central American countries.

Figure 2. Distribution of Adult Participants by Race

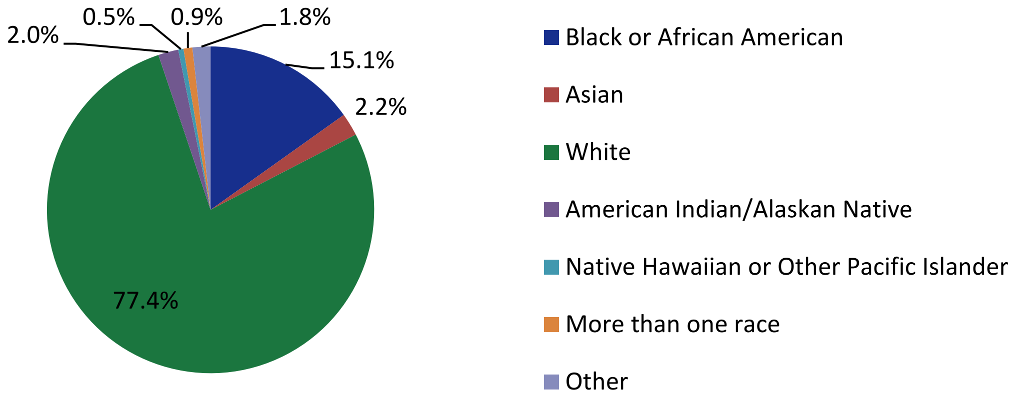


Table 3. Number and Percentage of Adult Participants by Ethnicity

Ethnicity	Number of Participants	%
Hispanic or Latino	658	13.4
Not Hispanic or Latino	4,009	81.6
Missing/unknown	246	5.0
Total	4,913	

Figure 3. Distribution of Pediatric Participants by Race

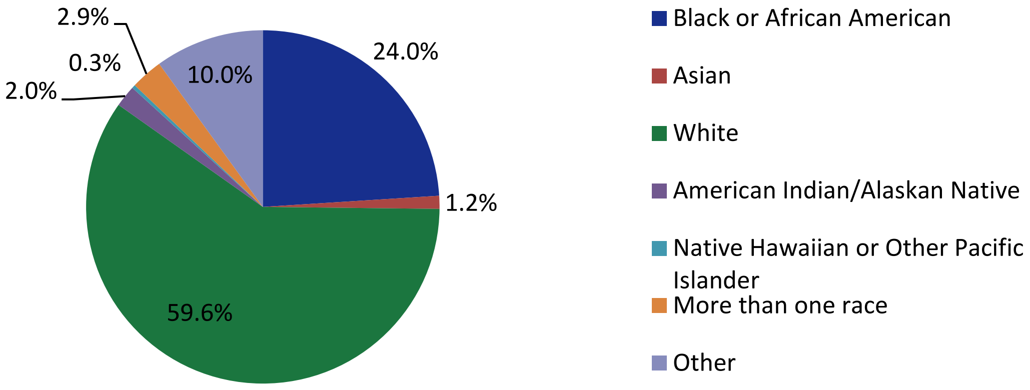


Table 4. Number and Percentage of Pediatric Participants by Ethnicity

Ethnicity	Number of Participants	%
Hispanic or Latino	1,287	53.6
Not Hispanic or Latino	1,027	42.8
Missing/unknown	88	3.7
Total	2,402	

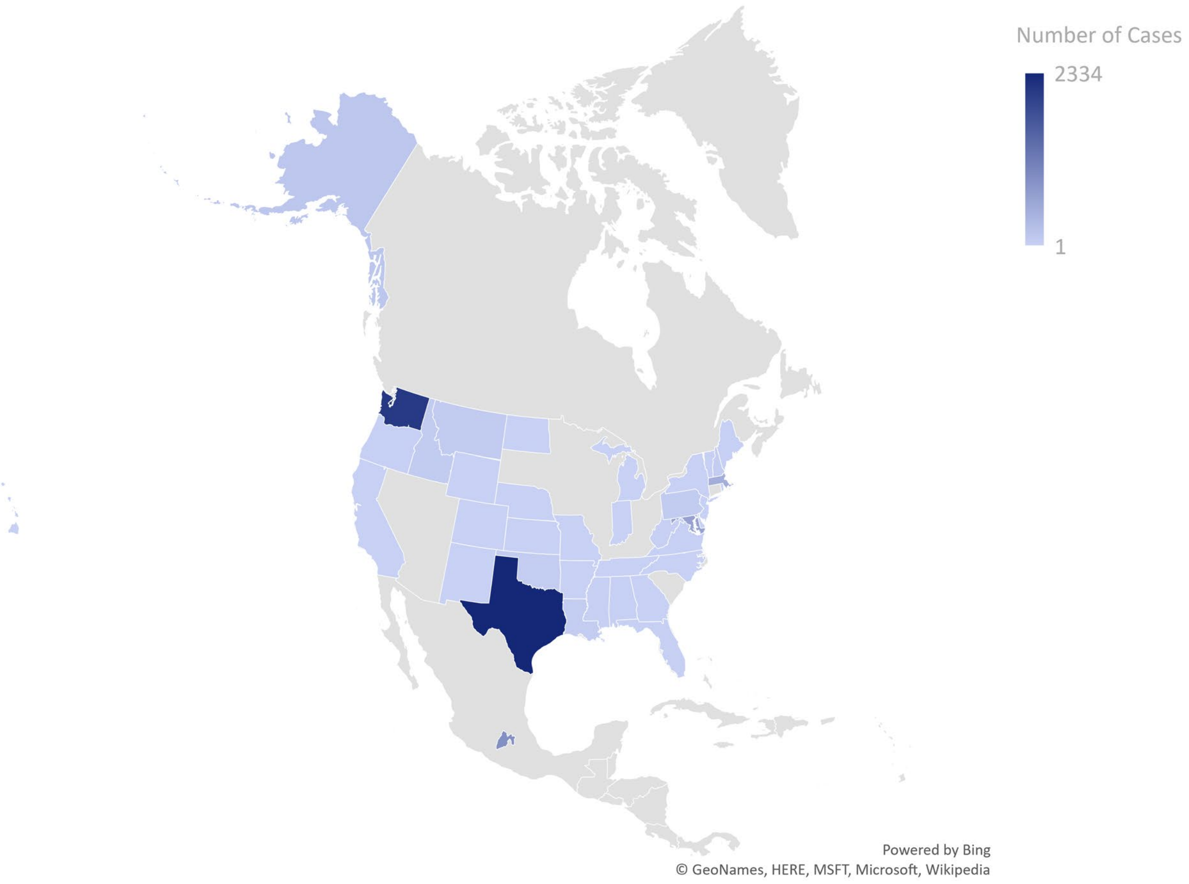
Residence and Geographical Location at Time of Injury

Table 5 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 10% of participants had missing or unknown data. Figure 4 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 darker colors.

Table 5. Type of Residence at the Time of Burn Injury

Type of Residence	Number of Participants	%
House/private residence	6,416	87.7
Nursing home	1	0.01
Adult home	12	0.2
Hotel/motel	5	0.1
Homeless	105	1.4
Missing/unknown	776	10.6
Total	7,315	

Figure 4. Geographical Location of Residence at Time of Burn Injury



Living Situation at Time of Injury

Figures 5 and 6 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 parent(s) or step-parent(s).

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

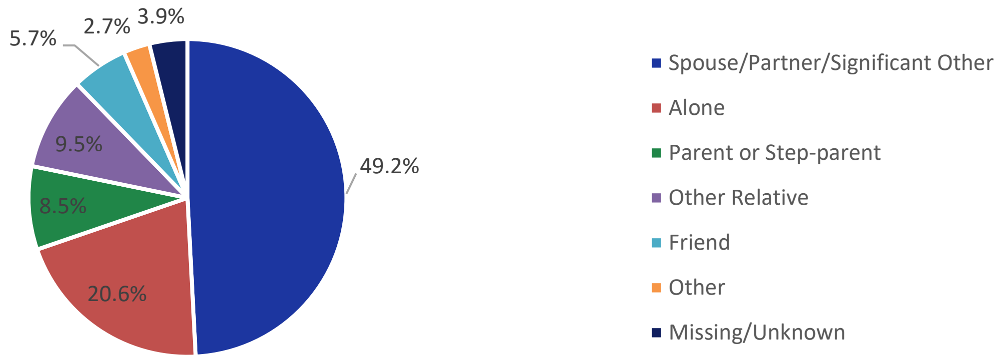
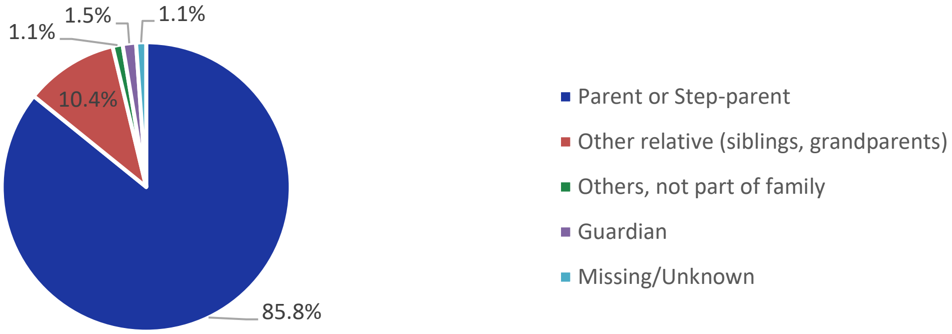


Figure 6. Distribution of Children Living With Another Person at the Time of Their Injury



Employment and School Status at Time of Injury

Table 6 shows the employment status of BMS participants, 18 years of age and older, at the time of their burn injury (*n* = 4,913). 4% of participants had missing or unknown data. The majority of adults were employed at the time of their injury. Table 7 shows the school status of children, 5–17 years of age, at the time of their burn injury (*n* = 1,383). The majority of children in this age group were enrolled in school at the time of their injury.

Table 6. Employment Status of Participants, 18 Years of Age and Older, at the Time of Their Injury

Employment Status	Number of Participants	%
Employed	2,957	60.2
Not employed	1,085	23.2
Retired	507	10.3
Homemaker/caregiver	64	1.3
Volunteer	11	0.2
Missing/unknown	234	4.8
Total	4,913	

Table 7. School Status of Participants, 5–17 Years of Age, at the Time of Their Injury

School Status	Number of Participants	%
In school	962	77.0
Not in school	191	15.3
Missing/unknown	230	16.6
Total	1,383	

Adults Reporting Pre-Injury Alcohol Use and Drug Use

Table 8 lists pre-injury alcohol and drug use for adults as measured by the CAGE for those with non-missing data. 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 9.0% for each. Figures 7 and 8 show the % of those with possible alcohol misuse and drug misuse by burn year and only includes those adults who had data for the CAGE assessments.

Table 8. Pre-Injury Alcohol and Drug Use

Pre-Injury Alcohol and Drug Misuse	Number of Participants	%
Potential alcohol misuse in past 12 months	681	11.4
Potential drug misuse in past 12 months	517	8.7

Figure 7. Percentage of People Indicating Potential Alcohol Misuse By Burn Year

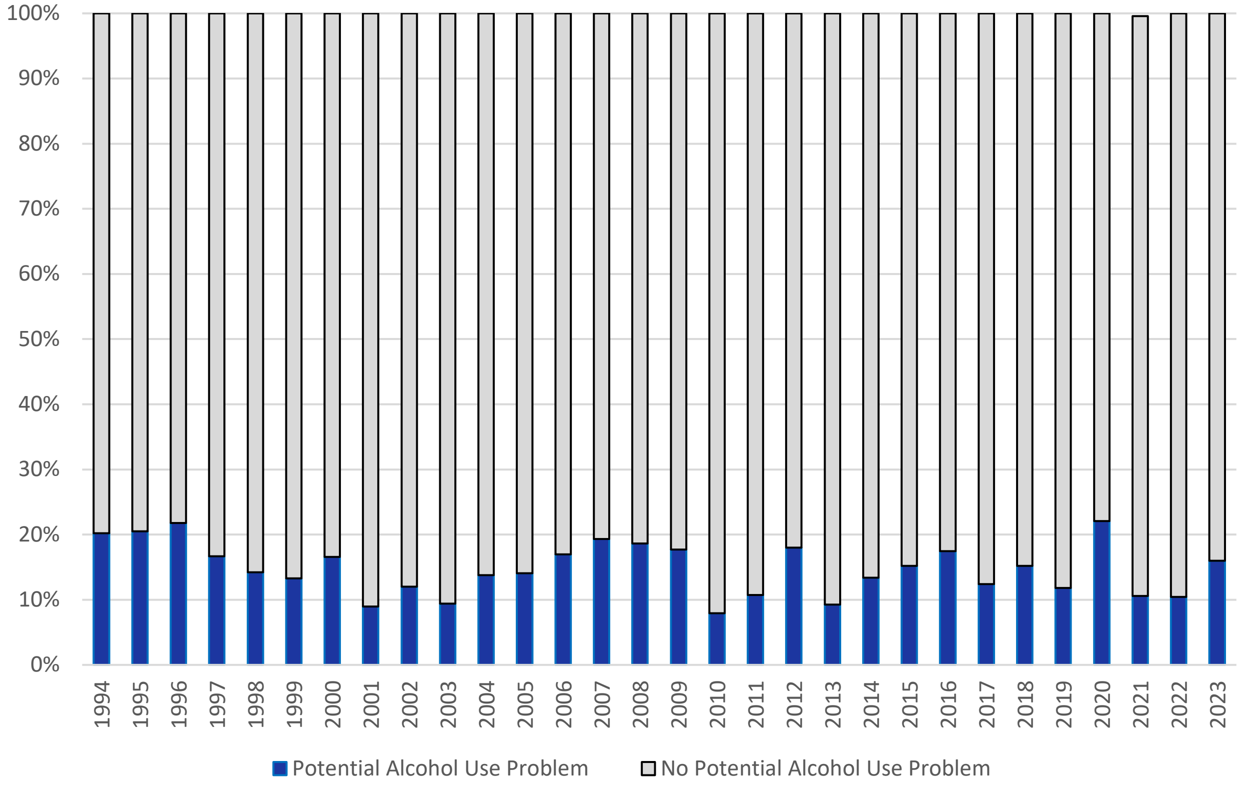
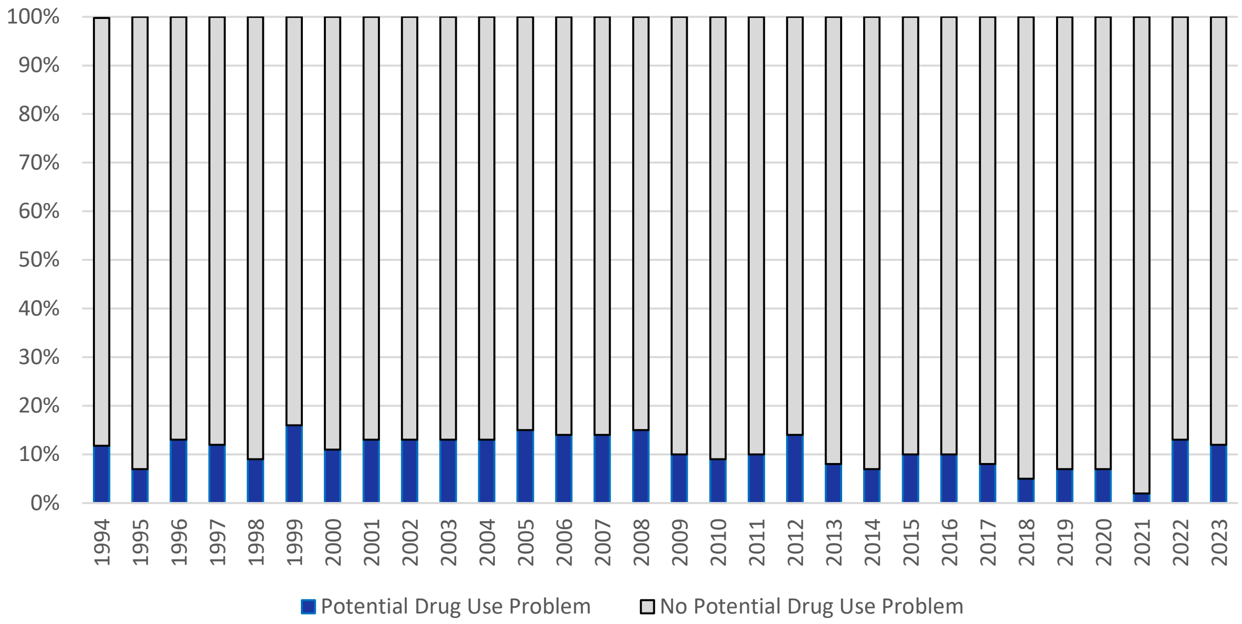


Figure 8. Percentage of People Indicating Potential Drug Misuse By Burn Year



Adults Reporting Pre-Existing Physical Problems

Table 9 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 (7.6% of the records collected since 2015 have missing data for this item).

Table 9. Pre-Injury Disability

Disability	Number of Participants	%
Pre-injury physical disability	204	17.2

Adults With History of Military Service

Table 10 identifies the prevalence of military service 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 (8.3% of the records collected since 2015 have missing data for this item).

Table 10. Pre-Injury History of Military Service

Military Service	Number of Participants	%
Past or present military service at time of burn	155	13.7

Characteristics of Burn Injury

Total Body Surface Area Burned

Figure 9 shows the number of participants in the BMS database by burn size. Among database records that reported burn size, 54.8% of participants had less than 20% TBSA burned. Only 7.0% of participants had burns on 60% or more TBSA.

Table 11 shows the percentage of participants in each category of total burn size. Very few (0.5%) participants had burn size that was unknown or not recorded.

Figure 9. Number of Participants by Burn Size Category (% TBSA Burned)

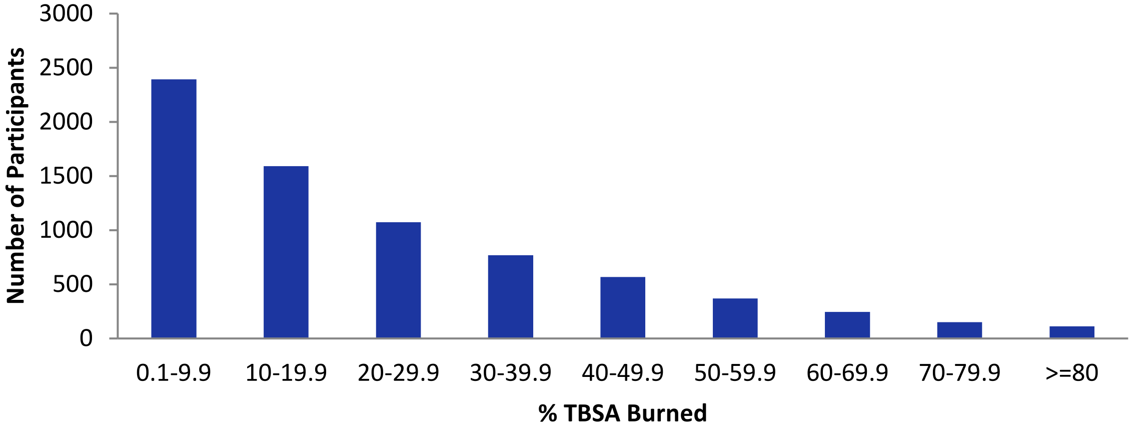


Table 11. Number and Percentage of Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Number of Participants	%
0.1–9.9	2,394	32.9
10–19.9	1,591	21.9
20–29.9	1,075	14.8
30–39.9	770	10.6
40–49.9	569	7.8
50–59.9	370	5.1
60–69.9	244	3.4
70–79.9	151	2.1
>=80	112	1.5
Missing/unknown	39	0.5
Total	7,035	

Burn Location and Graft Location on the Body

Table 12 presents data on the bodily location of burn injuries for participants in the BMS database while Table 13 presents data on the bodily location of grafting.

Table 12. Burn Injury Location

Location	Yes	%	No	%	Missing/ Unknown	%
Head/neck burn	3,949	54.7	3,292	44.3	74	1
Trunk burn	4,459	61.6	2,793	37.5	63	0.9
Perineum burn*	1,247	17.1	5,524	75.2	544	7.7
Arm burn (right, left, or bilateral)	4,867	69.6	2,388	30.2	60	0.3
Hand burn (right, left, or bilateral)	4,885	66.4	2,353	32.6	77	1.1
Leg burn (right, left, or bilateral)	4,289	58.9	2,962	40.3	64	0.9
Foot burn (right, left, or bilateral)	2,415	32.9	4,809	65.9	91	1.3

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

Table 13. Burn Graft Location

Location	Yes	%	No	%	Missing/ Unknown	%
Head/neck burn	1,295	18.1	5,853	79.6	167	2.3%
Trunk burn	2,800	38.7	4,362	59.2	153	2.1%
Perineum burn*	579	8.0	5,980	81.4	756	10.3%
Arm burn (right, left, or bilateral)	3,541	48.4%	3,622	49.5%	152	2.1%
Hand burn (right, left, or bilateral)	3,121	42.9	4,024	54.7	170	2.3%
Leg burn (right, left, or bilateral)	3,210	43.9	3,958	54.0	147	2.0%
Foot burn (right, left, or bilateral)	1,695	23.0	5,438	74.5	182	2.5%

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

Cause of Injury

Figure 10 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, 59.1% were injured by fire/flame. Table 14 presents data on the number and percentage of participants in each injury category. The "Other" burn category includes abrasions, hydrofluoric acid, frostbite, skin disease, and other causes. The BMS inclusion criteria have changed since the beginning of the program; frostbite and skin disease are no longer eligible causes of burn injury.

Figure 11 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 10. Distribution of Participants by Cause of Injury

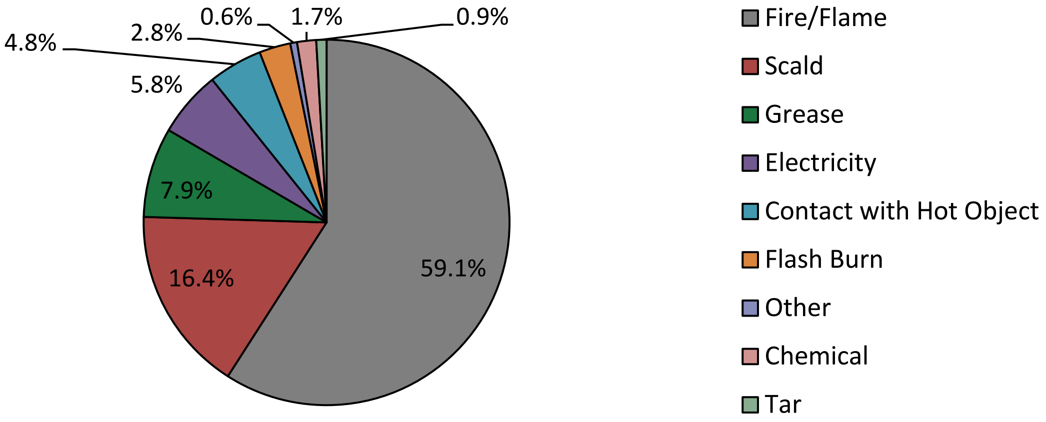
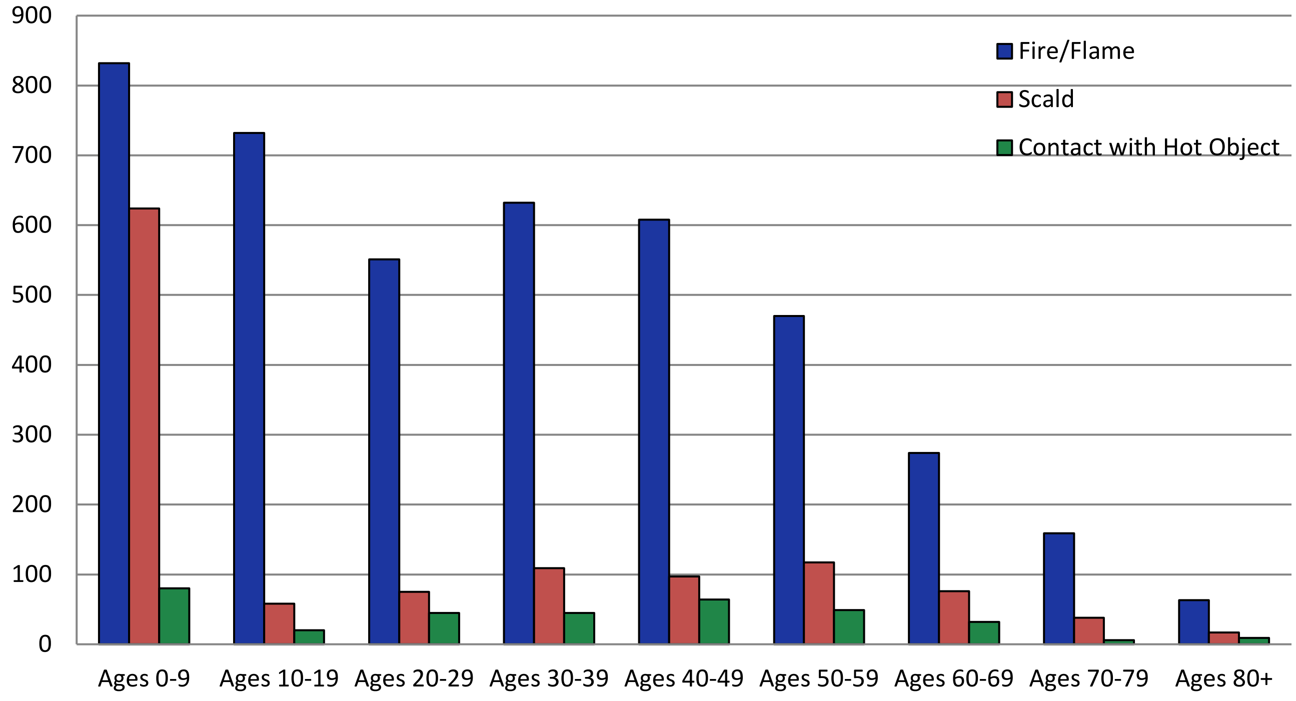


Table 14. Number and Percentage of Participants by Cause of Injury

Cause of Injury	Number of Participants	%
Fire/Flame	4,245	58.0
Scald	1,179	16.1
Grease	571	7.8
Electricity	419	5.7
Contact with Hot Object	344	4.7
Flash Burn	199	2.7
Chemical	43	0.6
Tar	121	1.7
Other	65	0.9
Unknown/Missing	129	1.8
Total	7,315	

Figure 11. Number of Participants by Cause of Injury and Age Group



Circumstances and Place of Injury

Table 15 and Figure 12 provide data on the circumstances of injury among participants in the BMS database. Data on the circumstances of injury were unknown for 2.2% of participants. Figure 12 is based on participants whose circumstances of injury were known. The majority of burn injuries in the database were considered nonintentional, 15.7% of which were related to employment. Almost 6% of burn injuries were considered intentional.

Table 16 identifies the place (closed/indoors versus open/outdoors) in which the injury occurred among participants in the BMS database. The majority of injuries occurred indoors. Figure 13 identifies the location at which the injury occurred by percent TBSA burned (based on available data).

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

Circumstance of Injury	Number of Participants	%
Non-intentional non-work related	3,852	52.7%
Non-intentional employment related	1,149	15.7%
Non-intentional recreation	969	13.2%
Non-intentional unspecified	762	10.4%
Suspected self-inflicted/suicide	160	2.2%
Suspected assault: domestic	151	2.1%
Suspected assault: non-domestic	87	1.2%
Suspected arson	22	0.3%
Missing/unknown	163	2.2%
Total	7,315	

Figure 12. Distribution of Participants by Circumstance of Injury

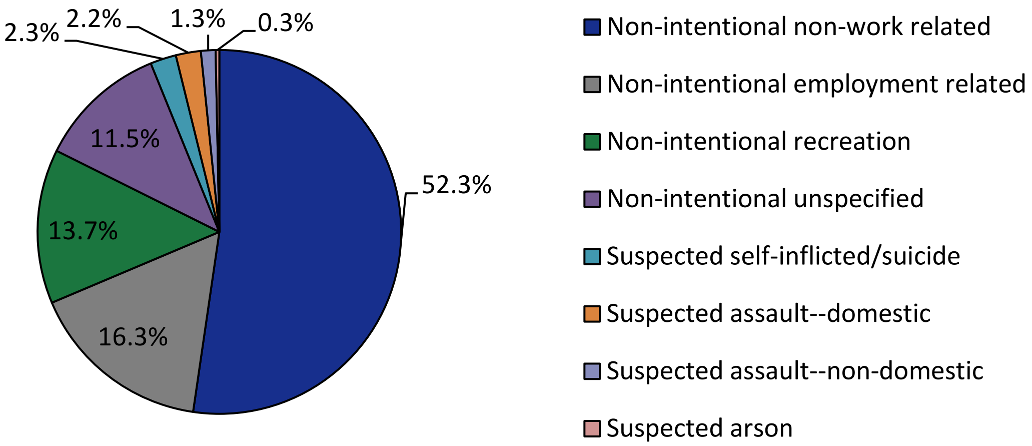
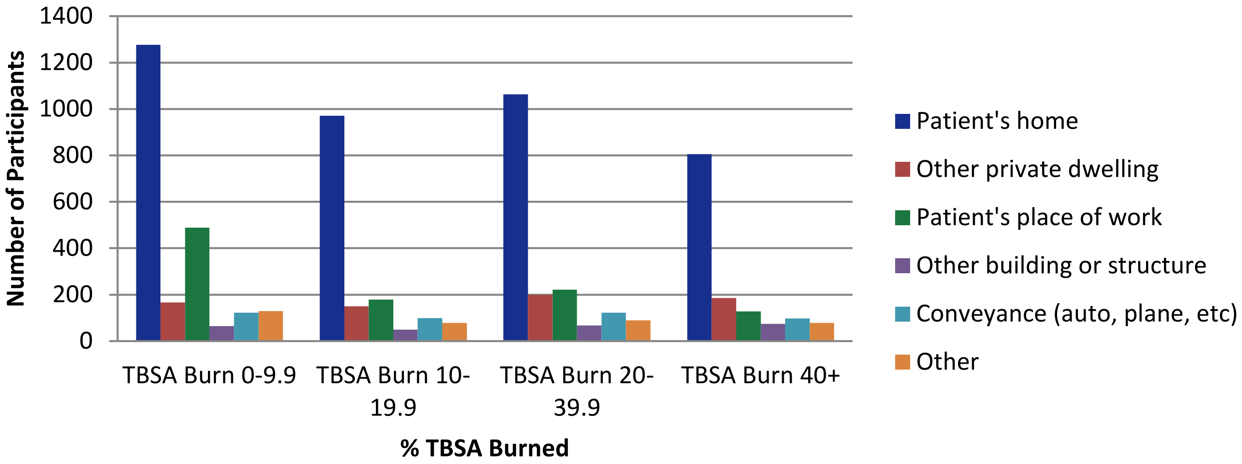


Table 16. Number and Percentage of Participants by Place of Injury

Place of Injury	Number of Participants	%
Closed/Indoors	4,357	66.8
Open/outdoors	2,841	43.5
Missing/unknown	117	1.8
Total	7,315	

Figure 13. Location of Injury Among Participants by Burn Size Category (% TBSA Burned)



Inhalation and Other Injuries

Table 17 identifies the incidence of inhalation injuries and other injuries among participants in the BMS database, as well as range of motion deficits. Table 18 provides data on inhalation injury and range of motion deficit by gender (based on available data).

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

Type of Injury	Number of Participants	%
Inhalation injury	1,098	15.0
Other injury	901	12.9
Range of motion deficit	3,568	53.1

Table 18. Percentage of Participants With Inhalation Injury and Range of Motion Deficit by Gender

Gender	Inhalation Injury %	Range of Motion Deficit%
Males	14.5	53.6
Females	16.2	51.6

Treatment Before Discharge

Length of Acute Care Hospital Stay

Figure 14 shows the average length of acute care hospital stay at the BMS Center per year among participants in the BMS database. Only 25 records (0.3%) in the database were missing data on the length of hospital stay. Figure 14 is based on available data. From 1993 to 2023, the average length of stay was 26 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 19 shows the average length of hospital stay by percent TBSA burned.

Figure 14. Average Length of Acute Care Hospital Stay Among Participants by Year (1993–2023)

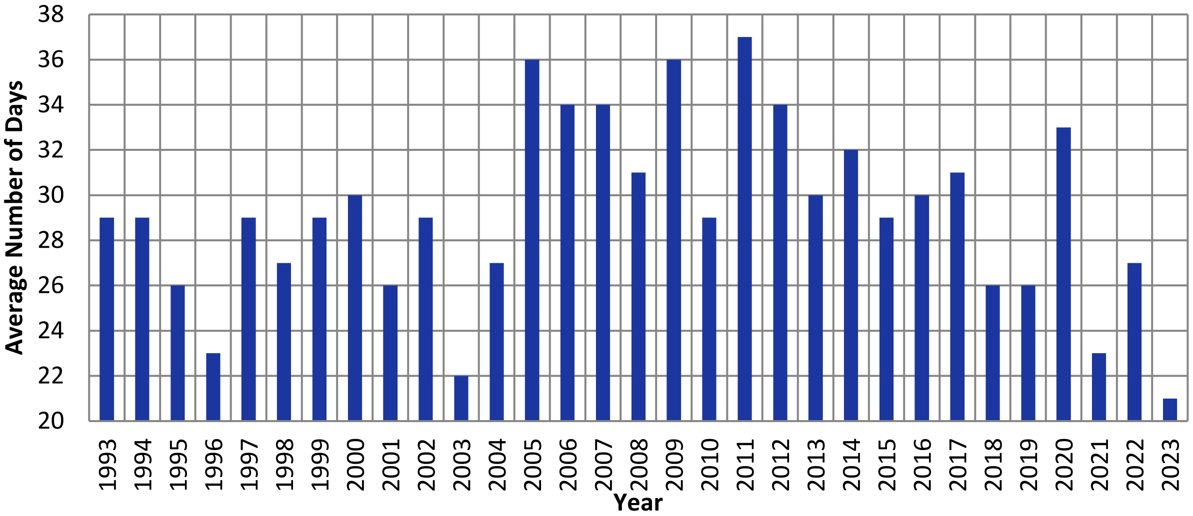


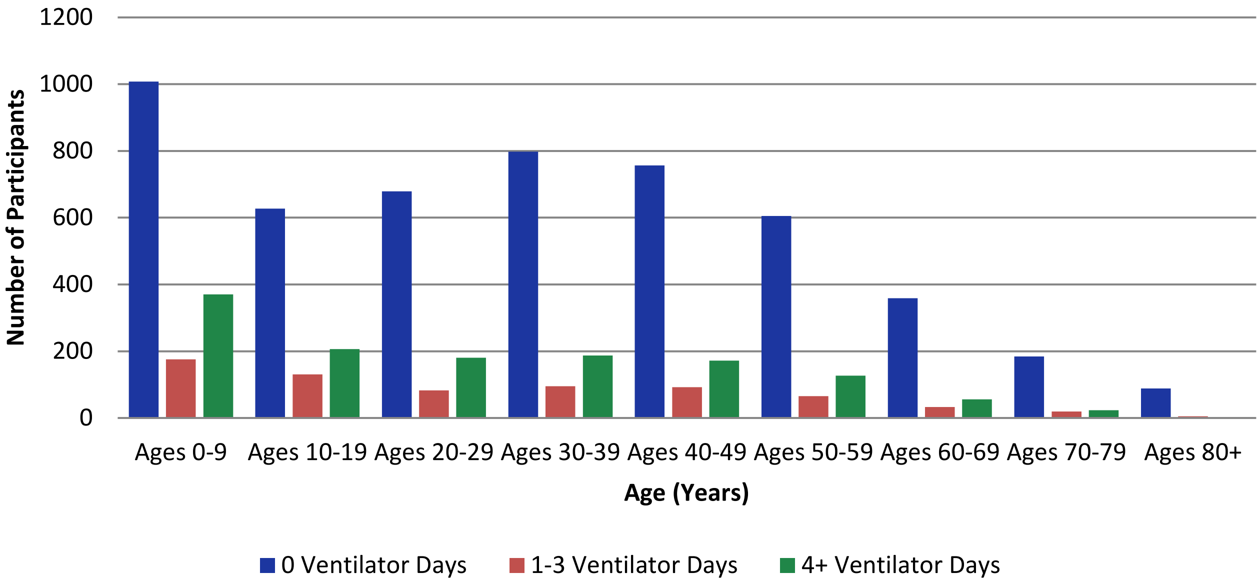
Table 19. Average Length of Acute Care Hospital Stay Among Participants by Burn Size Category (% TBSA Burned)

% TBSA Burned	Average Length of Hospital Stay (Days)
0–9.9	13.9
10–19.9	19.9
20–29.9	26.0
30–39.9	32.3
40–49.9	38.7
50–59.9	43.0
60–69.9	53.1
70–79.9	66.0
>80	108.3

Ventilator Days

Figure 15 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 was unknown or missing for 2.3% of the records in the database. Figure 15 is based on available data. The mean number of days on the ventilator was 3.7 days for the entire sample; the mean number of days for only those who had spent any time on a ventilator was 13.2 days.

Figure 15. Number of Participants and Days on Which They Spent on a Ventilator by Age Group



Inpatient Rehabilitation Days

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

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

Inpatient Rehabilitation Days*	Number of Participants	%
Did not go to rehab (0 inpatient rehab days)	5,122	85.8
1–10 days of rehab	186	3.2
11–20 days of rehab	299	5.0
≥21 days of rehab	296	5.0
Missing/unknown	65	1.1
Total	5,695	

*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 16 shows the distribution of participants in the BMS database by type of disposition at hospital discharge. Figure 16 is based on available data. Table 21 identifies the number and percentage of each type of disposition for the sample.

Figure 16. Distribution of Participants by Type of Disposition at Hospital Discharge

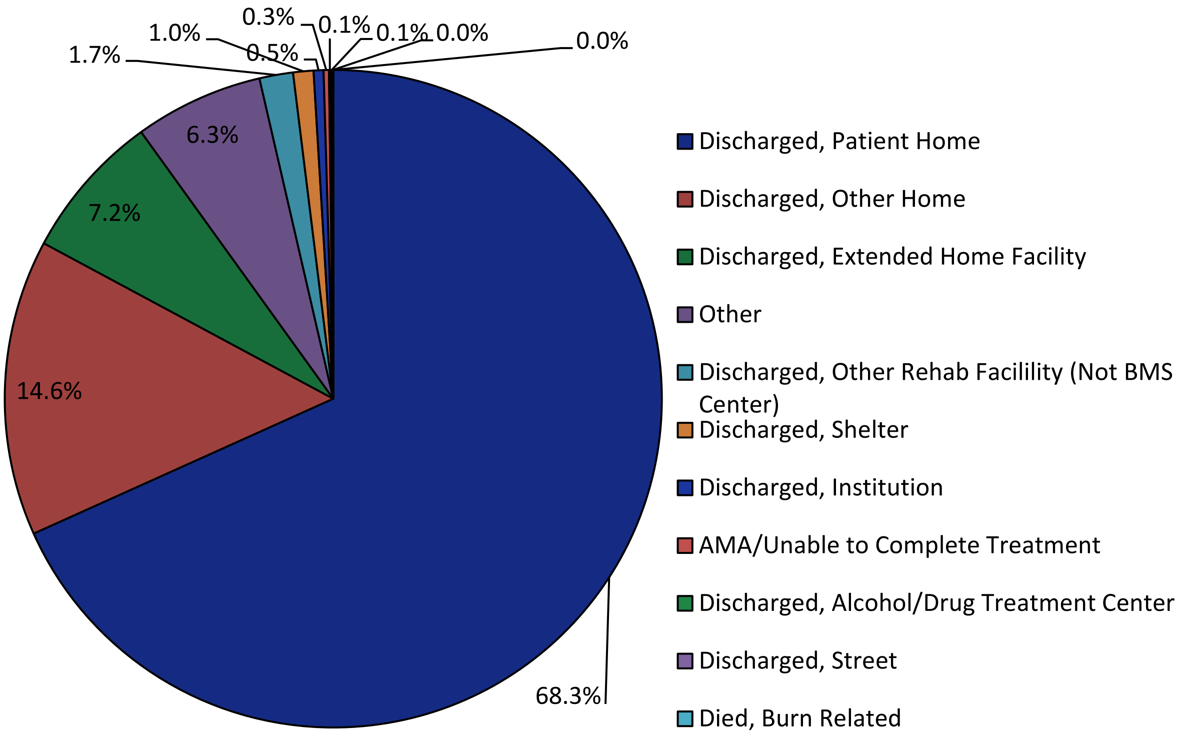


Table 21. Number and Percentage of Participants by Type of Disposition at Hospital Discharge

Disposition	Number of Participants	%
Discharged, patient home	4,917	67.2%
Discharged, other home	1,049	14.3%
Discharged, extended home facility	520	7.1%
Other	456	6.2%
Discharged, other rehab facility (not BMS Center)	119	1.6%
Discharged, shelter	72	1.0%
Discharged, institution	35	0.5%
Unable to complete treatment	19	0.3%
Discharged, alcohol/drug treatment center	6	0.1%
Discharged, street	7	0.1%
Died, burn related	1	0.0%
Died, not burn related	1	0.0%
Missing/unknown	113	1.5%
Total	7,315	

Primary Sponsor of Care at Discharge

Table 22 identifies the primary sponsor of hospital care among participants in the BMS database at the time of hospital discharge. Data for this variable was unknown or missing for almost 11% of the records in the database.

Table 22. 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	1,746	26.3
Philanthropy; private support	1,075	16.2
Medicaid	1,174	17.7
Worker's compensation	733	11.1
Medicare	677	10.2
Self-pay (public support)	613	9.3
Other	538	8.1
Champus/Tri-Care	31	0.5
VA	31	0.5
Missing/Unknown	697	10.5
Total	7,315	

Status of Follow-Up Assessment

Table 23 identifies the number and percentage of each type of follow-up status at 6-, 12-, and 24-months. Data consists of all participants for whom follow-up data is available and 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 2020). Figure 17 shows a graph of the number of people eligible and then the number of people enrolled. Figure 18 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 reconsent to the study before they provide any follow-up data. Figure 19 shows follow-ups completed by racial/ethnic group and is based on available data.

Table 23. Number and Percentage of Participants by Follow-Up Status and Time-Point

		6 Months		12 Months		24 Months	
Follow-Up Status	**Hospital Discharge**	**Number of Participants**	**%**	**Number of Participants**	**%**	**Number of Participants**	**%**
Total number eligible:	9,809						
Total number enrolled:	7,315						
Data collected/Follow-up Complete		5,133	75.8	4,484	73.9	3,796	66.7
Death due to burn-related complications		27	0.4	23	0.4	22	0.4
Death due to non-burn complications		26	0.4	51	0.8	76	1.3
Unable to locate		442	6.5	488	8.0	768	13.5
Refused this assessment		64	0.9	51	0.8	88	1.6
Unable to test/medically incapable of responding		18	0.3	23	0.4	35	0.6
Failed to respond		952	14.1	814	13.4	764	13.4
Did not consent to future assessment/withdrew		78	1.2	93	1.5	100	1.8
Incarcerated		7	0.1	25	0.4	28	0.5
Still in hospital (not discharged yet)		13	0.2	13	0.2	7	0.1
Other		14	0.2	4	0.1	5	0.1

Figure 17. Number of People Eligible for the BMS study and Number of People Enrolled by Year

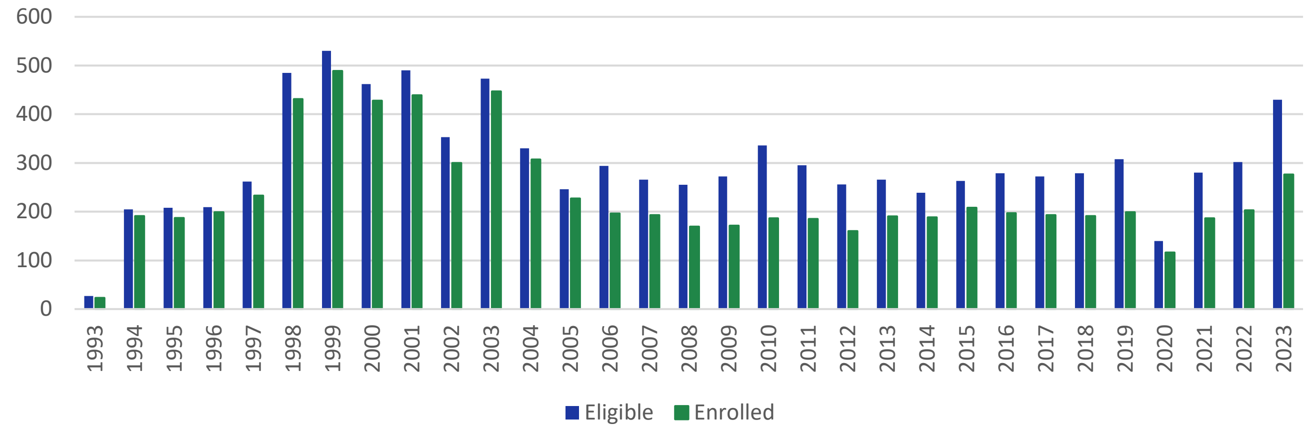


Figure 18. Number of Participants With Data at Long-Term Follow-Ups

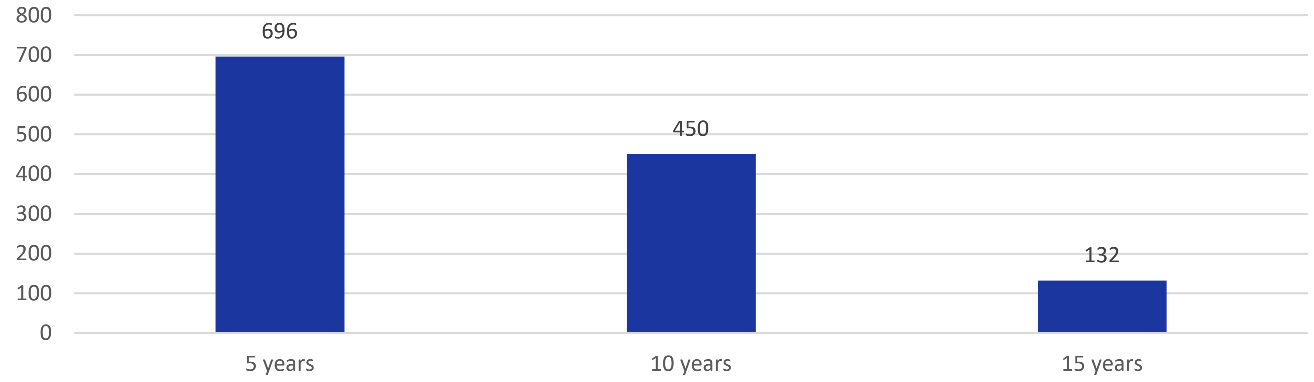
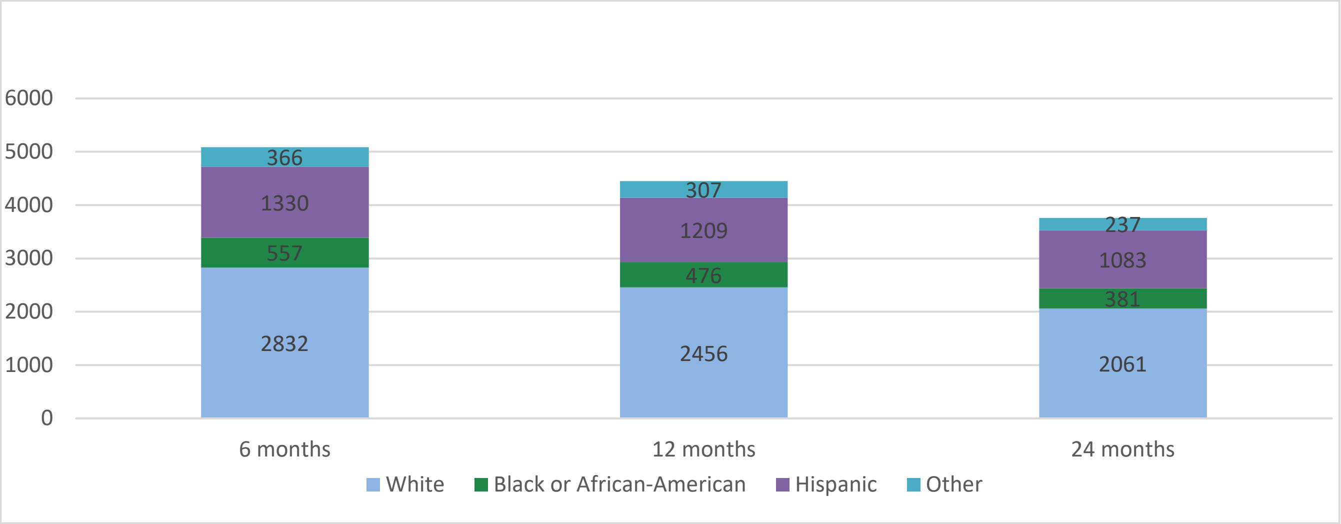


Figure 19. Follow-Ups Completed by Racial/Ethnic Group



Physical Outcomes After Burn Injury

Physical Issues in Adults

Table 24 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 24. Physical Issues in Adults After Burn Injury

	6 Months		12 Months		24 Months		5 years	
Physical Issues*	*N*	%	*N*	%	*N*	%	*N*	%
Hearing loss	122	15.6	89	15.2	111	19.3	42	20.8
Change in voice	89	11.3	71	10.9	64	11.2	26	12.8
Vision or eye problems	115	14.6	82	12.5	69	12	32	15.6
Difficulty with memory	219	28.2	186	28.4	161	28.2	72	35.5
Difficulty with thought processing	169	21.6	148	22.6	132	23.3	51	25
Numbness, pins and needles or burning sensations in burn scar	547	69.4	423	63.3	303	52.2	111	54.2
Trouble with balance	230	29.1	177	26.9	164	28.5	69	33.3
Varicose veins	95	12.3	92	14.2	77	13.6	24	11.8
Difficulty with breathing when doing regular activities	146	18.6	124	18.8	107	18.6	36	17.3
Joint pain	315	40.2	271	41.2	263	45.8	89	42.8
Cold Intolerance	258	33.2	208	31.7	187	32.4	69	33.5
Difficulty in hot environments	266	35.1	250	38.2	234	40.9	97	47.1

*Data collection for these variables began in 2015.

Physical Issues in Children

Table 25 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 25. Physical Issues in Children After Burn Injury

	6 Months		12 Months		24 Months		5 years	
Problems with…	*N*	%	*N*	%	*N*	%	*N*	%
Seeing	16	6.5	18	7.9	18	8.4	24	20.9
Hearing	5	2.0	4	1.8	12	5.6	8	7.0
Learning and understanding	23	9.4	21	9.2	38	17.8	28	24.6
Controlling emotions or behavior	82	33.3	62	27.3	71	33.2	41	35.7
Sleeping	73	29.6	43	18.9	32	15.0	22	19.1
Breathing	18	7.3	12	5.2	11	5.2	10	8.7
Chronic open skin areas	44	17.8	39	16.9	26	12.1	9	7.8
Other skin problems	26	10.7	21	9.2	23	10.8	9	7.8

Physical and Mental Health Outcomes among Adults

Table 26 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[4], 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 20 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 26. 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	45.6 (10.0)	752	47.9 (9.7)	648	48.1 (9.7)	570	47.6 (9.4)	206
Sleep Disturbance	51.1 (10.2)	761	49.3 (10.1)	650	49.4 (10.8)	572	49.9 (10.2)	209
Fatigue	48.8 (11.2)	761	48.4 (11.3)	647	48.3 (11.6)	562	49.3 (11.0)	207
Anxiety	50.3 (10.2)	758	49.7 (10.0)	651	50.1 (10.6)	567	50.5 (10.8)	206
Depression	49.8 (9.8)	755	48.9 (9.9)	648	49.1 (10.1)	565	49.2 (10.0)	208
Pain interference	52.9 (10.3)	752	50.9 (10.1)	649	50.1 (10.1)	566	50.8 (10.0)	206

*Data collected since 2015

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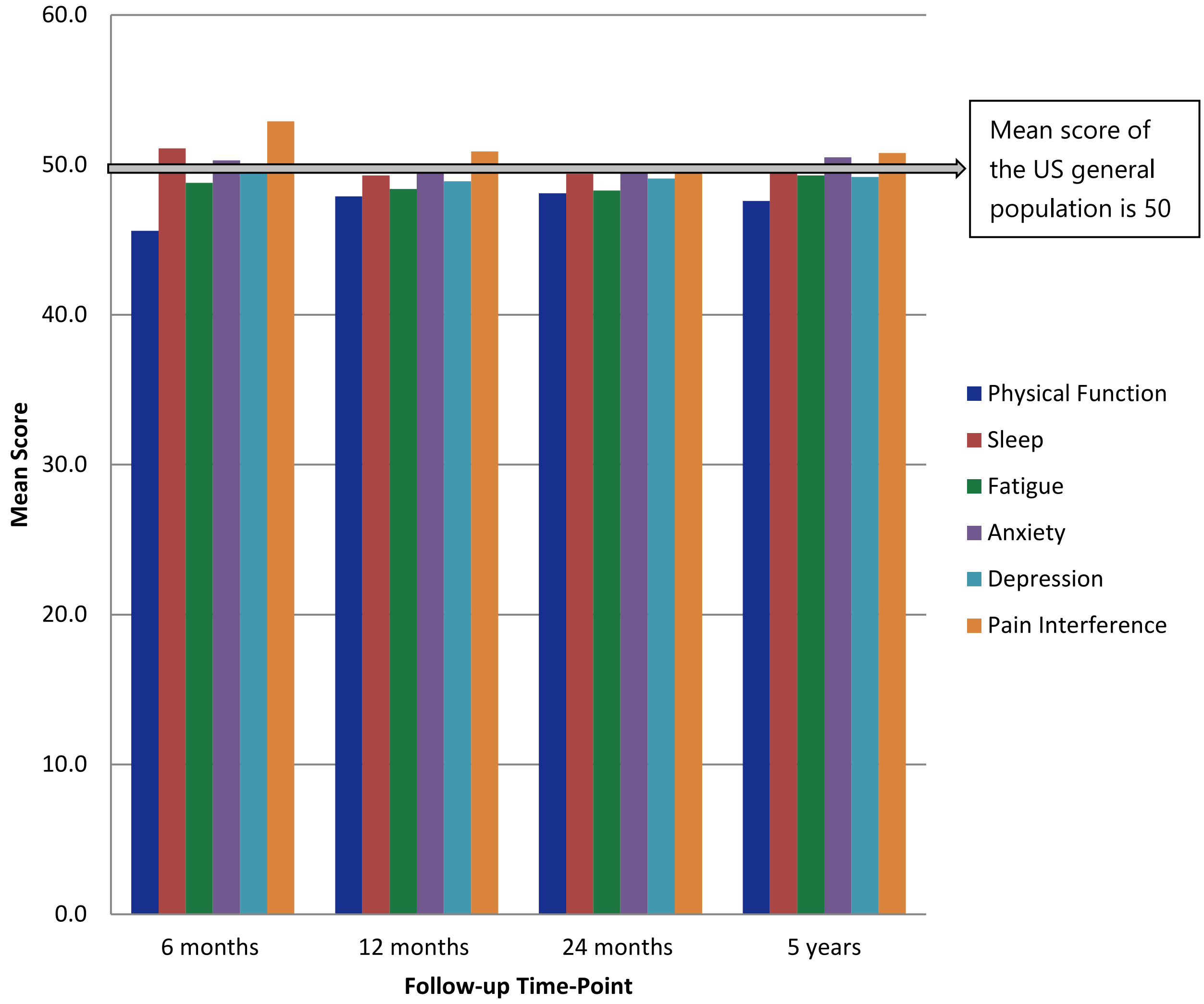
[4] For more information on PROMIS, see http://www.healthmeasures.net/explore-measurement-systems/promis

Figure 20. Mean Outcome Scores by Time-point for Adult BMS Participants



Functional Outcomes After Burn Injury

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

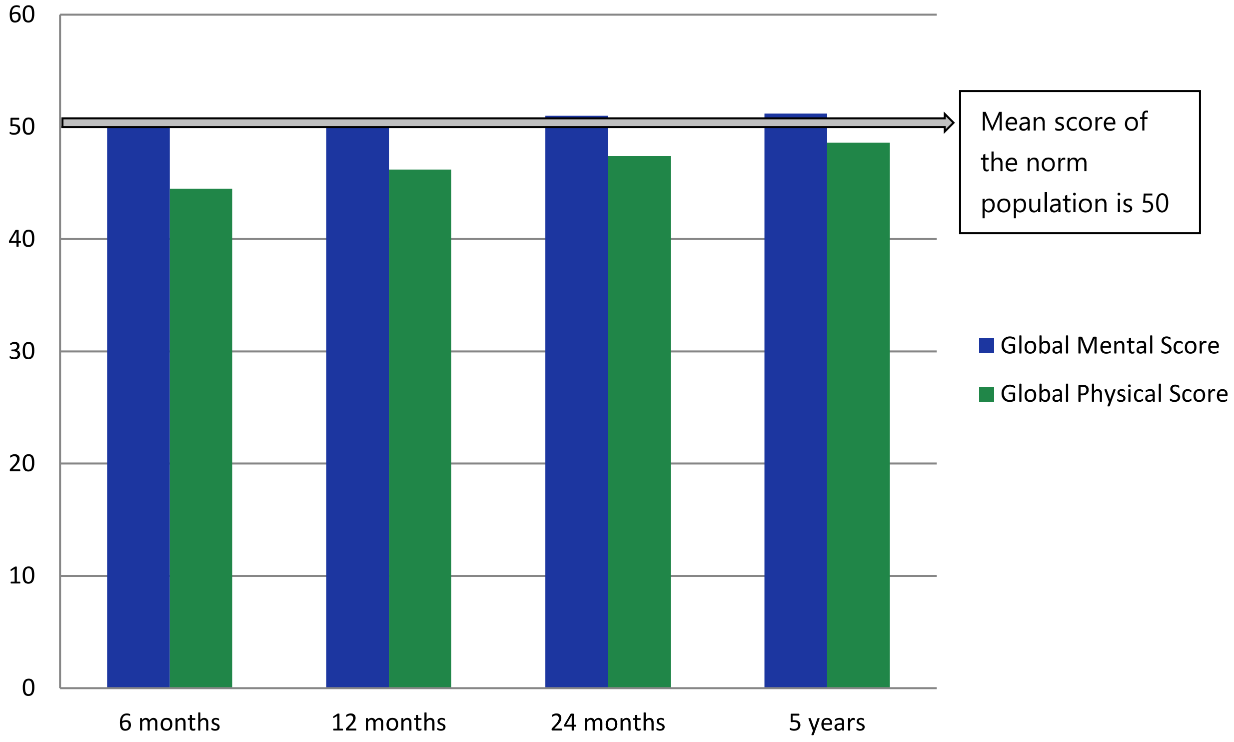
Table 27 presents the mean PROMIS-Global/VR12/SF-12 Mental Health Component (MCS) and Physical Health Component (PCS) scores for adult participants, in the BMS database at each follow-up time-point. The PROMIS-Global/VR-12/SF-12 are sets of questions that clinicians ask patients to understand how people 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 and from the VR-12 to the PROMIS-Global in 2022. The data presented here presents MCS and PCS scores as collected by all three measures, with the VR-12 and SF-12 scores cross-walked to the PROMIS-Global metric**.** For comparison purposes, Figure 21 presents the BMS and norm (or general) population scores cross-sectionally by time-point.

Table 27. Mean PROMIS Global/VR-12/SF-12 Scores Among Adult BMS Participants

Mean PROMIS Global/VR-12/SF-12* Scores, Adults	6 Months		12 Months		24 Months		5 Years	
	Mean	*N*	Mean	*N*	Mean	*N*	Mean	*N*
Global Mental Score	50.5	2,130	50.8	1,927	51.0	1,666	51.2	433
Global Physical Score	44.5	2,130	46.2	1,924	47.4	1,664	48.6	433

*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 21. PROMIS-Global/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).
**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 28 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* = 4,913), and is based on only available data. Table 29 presents data on the post-injury school status at follow-up of children, 5–17 years of age, in the BMS database (*n* = 1,296). Like employment status for adults, data on school status among children have not been collected during the entire span of the BMS. Therefore, Table 29 is based on only available data.

Table 28. Employment Status After Burn Injury Among Adult Participants (≥18 Years of Age)

	6 Months		12 Months		24 Months	
Employment Status*	**Number of Participants**	**%**	**Number of Participants**	**%**	**Number of Participants**	**%**
Working	1,332	35.4	1,370	41.6	1,262	45.4
Not Working	1,997	53.1	1,527	46.3	1,178	42.3
Homemaker/Caregiver	44	1.2	44	1.3	38	1.4
Volunteer	19	0.5	9	0.3	12	0.4
Retired	369	9.8	345	10.5	293	10.5

*Data collection for these variables began in 2009.

Table 29. School Status After Burn Injury Among Child Participants (5–17 Years of Age)

	6 Months		12 Months		24 Months	
School Status*	**Number of Participants**	**%**	**Number of Participants**	**%**	**Number of Participants**	**%**
In school	705	82.5	576	77.4	504	74.1
Not school	150	28.9	168	32.6	176	35.6

*Data collection for these variables began in 2009.

Burn Model System Data Collection

The Burn Model System started collecting data on new variables and measures in 2015 and updated the data collection forms in 2023. These forms use psychometrically sound, standardized instruments, such as those developed by the PROMIS initiative, which is funded by the National Institutes of Health (NIH). Table 30 describes the instruments and what they measure (i.e., domains) and provides additional information.

Table 30. Summary of New BMS Data Collection Instruments and Measures

Measure	Time-Point Administered	Age Group (Years) Administered To	BMS or Standardized Measure?
Domain: Demographics (including income, marital status, living situation, work status, school status, etc.)			
Demographics	Discharge and all follow-ups	Proxy (ages 0–17); self-report (ages ≥13)	BMS
Domain: Burn Injury Information			
Medical Record Abstraction Form	Discharge	All ages	BMS
Burn Injury Follow-Up	All follow-up points, not pre-burn (administered at discharge) or discharge	Proxy (ages 0–17); self-report (ages ≥13)	BMS
Domain: Medical Conditions			
Review of Systems	Pre-burn (administered at discharge), discharge, and all follow-ups	Ages ≥18	BMS
Child Health Conditions	All follow-ups, not pre-burn (administered at discharge) or discharge	Proxy (ages 0–17); self-report (ages 13–17)	Standardized
Domain: Health Related Quality of Life			
PROMIS Global	Pre-burn (administered at discharge), and all follow-ups	Ages ≥18	Standardized
Domain: Global Health (including depression, fatigue, anxiety, peer relationships, anger)			
PROMIS 29	All follow-ups, not pre-burn (administered at discharge) or discharge	Ages ≥18	Standardized

Measure	Time-Point Administered	Age Group (Years) Administered To	BMS or Standardized Measure?
PROMIS 25	All follow-ups, not pre-burn (administered at discharge) or discharge	Self-report (ages 8–17); proxy (ages 8-17)	Standardized
Domain: Community Participation			
Community Integration Questionnaire	Pre-burn (administered at discharge) and all follow-ups	Self-report ages ≥14; proxy (ages 14-17)	Standardized
Domain: Depression			
NIH Toolbox Sadness	All follow-ups, not pre-burn (administered at discharge) or discharge	Proxy (ages 3–7)	Standardized
Domain: Anger			
PROMIS Anger	All follow-ups, pre-burn (administered at discharge) or discharge	Proxy (ages 8–17)	Standardized
NIH TB Anger	All follow-ups, not pre-burn (administered at discharge) or discharge	Proxy (ages 3–7)	Standardized
Domain: Stigma/Body Image			
Neurological-Quality of Life (Neuro-Qol) Stigma Measure	All follow-ups, not pre-burn (administered at discharge) or discharge	Ages ≥18	Standardized
Body Image	All follow-ups, pre-burn (administered at discharge) or discharge	Proxy (ages 0–17); self-report (ages 8–17)	From Burn Outcomes Questionnaire

Measure	Time-Point Administered	Age Group (Years) Administered To	BMS or Standardized Measure?
Domain: Itch			
PROMIS Itch Interference & PROMIS Itch Mood and Sleep	Discharge and all follow-ups, not pre-burn (administered at discharge)	Ages ≥18	Standardized
Pain and Itch	All follow-ups, not pre-burn (administered at discharge) or discharge	Proxy (ages 0–7)	BMS
Itch (PROMIS items modified for the BMS)	All follow-ups, not pre-burn (administered at discharge) or discharge	Proxy (ages 0–17); self-report (ages 8–17)	BMS
Domain: Posttraumatic Stress Disorder			
Primary Care PTSD Screen for DSM-5 (PC-PTSD-5)	All follow-ups, not pre-burn (administered at discharge) or discharge	Ages ≥18	Standardized
Child Posttraumatic Stress Disorder Symptom Scale	All follow-ups, not pre-burn (administered at discharge) or discharge	Self-report (ages 8–17)	Standardized
Domain: Drug/Alcohol/Medication Use			
CAGE Alcohol/Drug Use	Discharge and all follow-ups	Ages ≥18	Standardized for alcohol; modified by BMS for drug use
Pain Medication	Pre-burn (administered at discharge) and all follow-ups	Proxy (ages 0–17); self-report (ages ≥13)	BMS
Domain: Posttraumatic Growth			
Posttraumatic Growth Inventory	All follow-ups, not pre-burn (administered at discharge) or discharge	Ages ≥18	Standardized
Posttraumatic Growth Inventory for Children	All follow-ups, not pre-burn (administered at discharge) or discharge	Self-report (ages 8–17)	Standardized
Domain: Physical Function			
PROMIS Physical Function Upper Extremity	All follow-ups, not pre-burn (administered at discharge) or discharge	Proxy (ages 8–17)	Standardized

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

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 22 and Figure 23 represent what data have been collected, and when, for adults and pediatrics, respectively. These timelines include the changes made to the data collection forms in 2023.

Figure 22. Timeline of Burn Model System Variable and Measure Administration, Adults

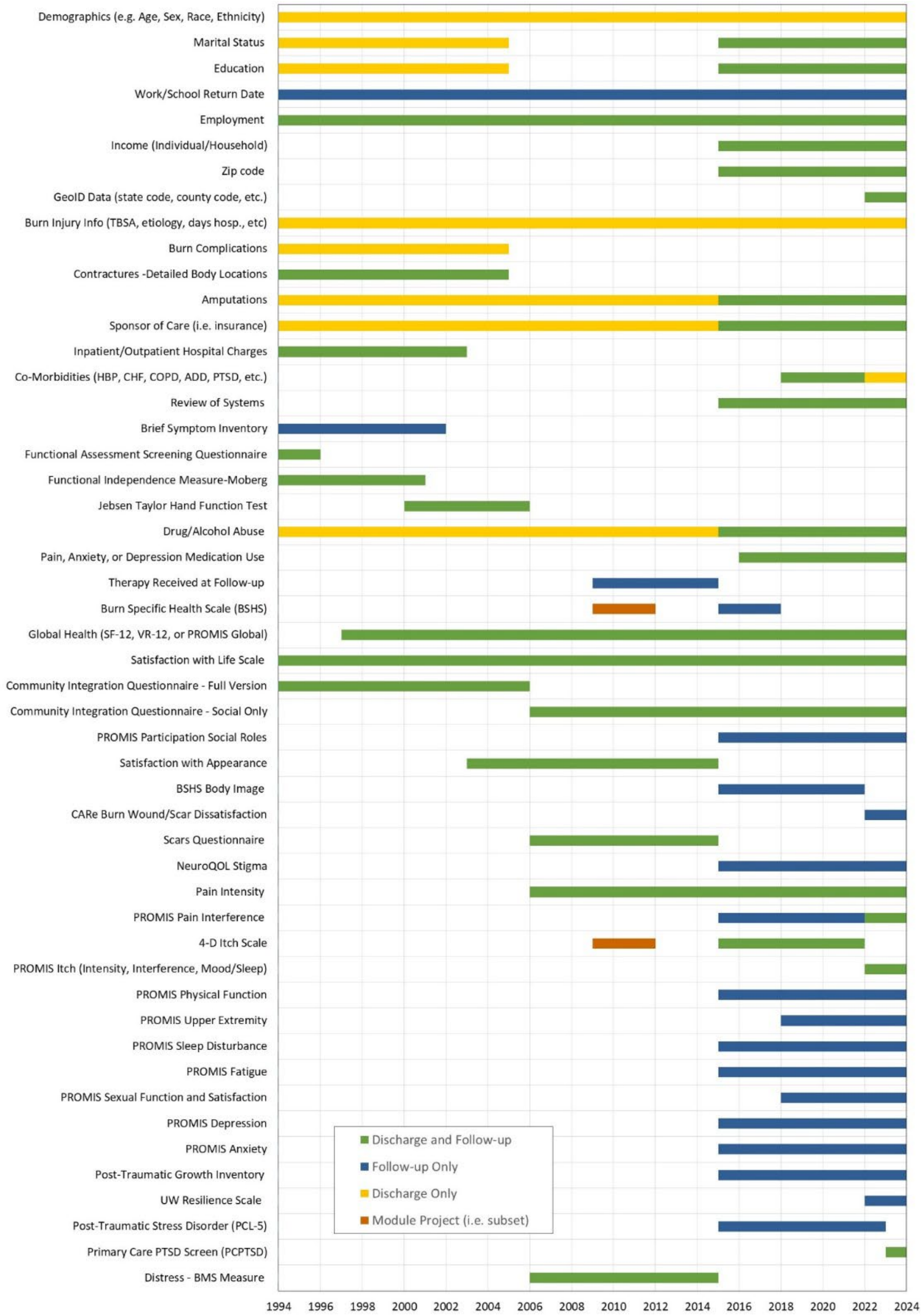
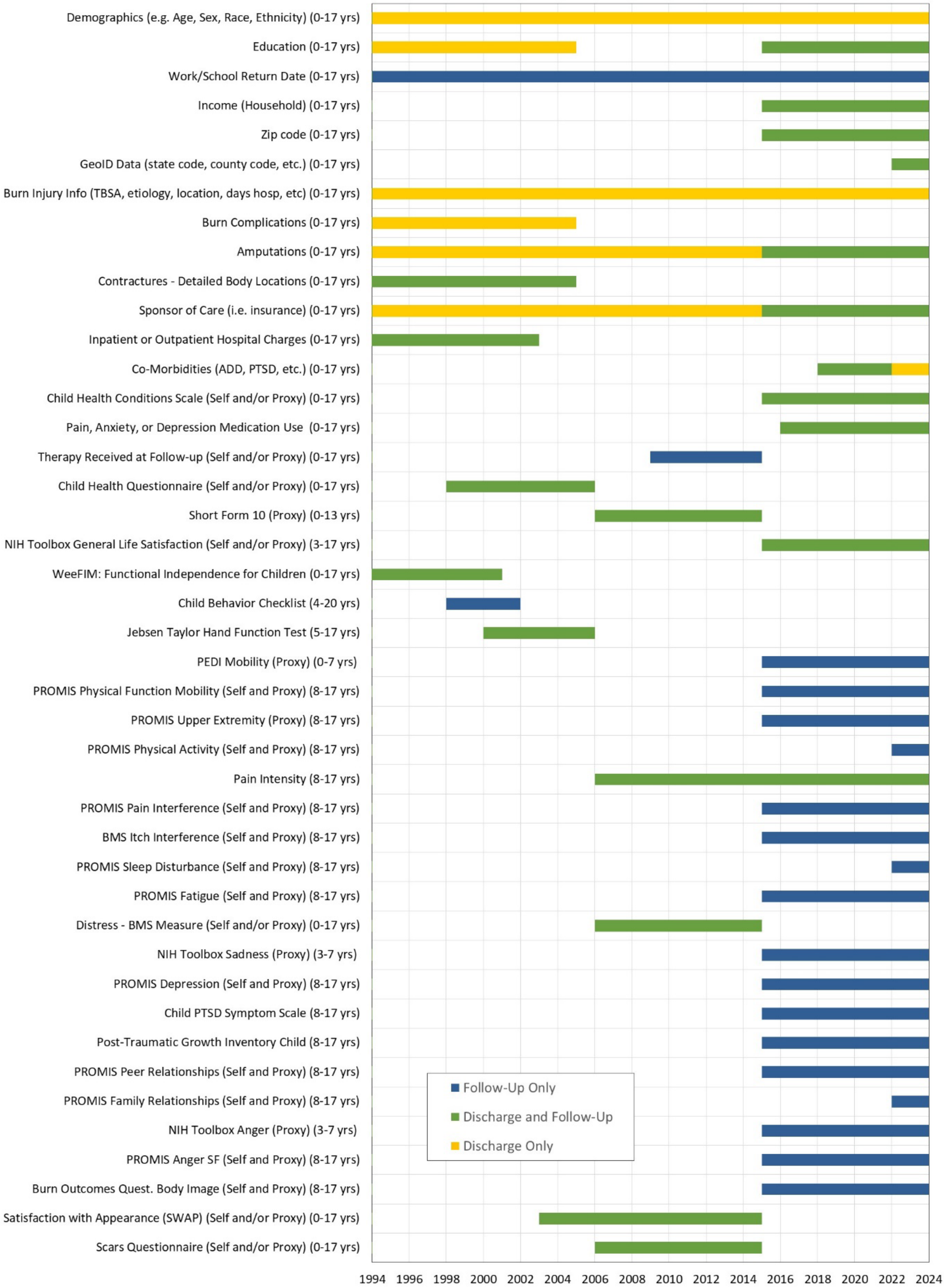


Figure 23. Timeline of Burn Model System Variable and Measure Administration, Pediatrics



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. Go to https://burndata.washington.edu/about-database
2. Click the link at the bottom of the page, under the heading Public Access, and fill out the data use agreement.
3. Access the linked de-identified dataset.

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 injury[5].
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)

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[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.