

Burn Model System Summary Report

1994–2017

This report contains information, tables, and figures about the data contained in the Burn Model System National Database, collected from 1993 to 2017. 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.

2018

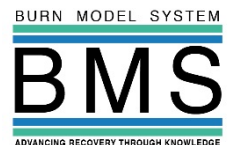


Table of Contents

| | |
|---|----|
| Introduction..... | 1 |
| Burn Model System Centers..... | 3 |
| Boston-Harvard Burn Injury Model System (BHBIMS)..... | 3 |
| North Texas Burn Rehabilitation Model System (NTBRMS)..... | 3 |
| Pediatric Burn Injury Rehabilitation Model System | 4 |
| Northwest Regional Burn Model System (NWRBMS)..... | 4 |
| Burn Model System National Data and Statistical Center (BMS NDSC)..... | 5 |
| Summary of Burn Model System Findings 1994–2017 | 6 |
| Cause of Injury..... | 6 |
| Demographics..... | 7 |
| Age Groups and Gender..... | 7 |
| Race and Ethnicity..... | 8 |
| Residence and Geographical Location at Time of Injury..... | 9 |
| Living Situation at Time of Injury..... | 10 |
| Employment and School Status at Time of Injury..... | 11 |
| Adults Reporting Pre-Injury Alcohol Use and Drug Use..... | 11 |
| Participants Reporting Pre-Existing Physical Disability..... | 12 |
| Participants Reporting Psychiatric Treatment in the Year Prior to the Injury..... | 12 |
| Characteristics of Burn Injury..... | 13 |
| Total Body Surface Area Burned | 13 |
| Burn Location on the Body..... | 14 |
| Total Body Surface Area Grafted..... | 14 |
| Graft Location | 15 |
| Cause of Injury..... | 15 |
| Circumstances and Place of Injury..... | 17 |
| Inhalation and Other Injuries..... | 18 |
| Treatment Before Discharge..... | 19 |
| Length of Acute Care Hospital Stay..... | 19 |
| Ventilator Days..... | 20 |
| Inpatient Rehabilitation Days | 20 |
| Hospital Discharge Data..... | 21 |
| Hospital Disposition..... | 21 |
| Primary Sponsor of Care at Discharge..... | 23 |
| Status of Follow-Up Assessment..... | 24 |
| Treatment After Discharge | 26 |
| Burn-Related Surgeries and Therapy Use..... | 26 |
| Physical Outcomes After Burn Injury..... | 27 |
| Physical Issues in Adults | 27 |
| Physical Issues in Children | 28 |
| Physical Function, Sleep, and Fatigue among Adults | 29 |
| Functional Outcomes After Burn Injury..... | 30 |
| Veterans Rand-12/SF-12 Mental and Physical Health Scores | 30 |

| | |
|--|----|
| Social Outcomes After Burn Injury | 32 |
| Employment Status and School Status..... | 32 |
| New Burn Model System Data Collection | 33 |
| Archived Burn Model System Data | 39 |
| Using the Burn Model System National Database..... | 40 |
| How Do You Request Data?..... | 40 |

List of Figures

| | |
|--|----|
| Figure 1. Number of Participants by Gender and Age Group..... | 7 |
| Figure 2. Distribution of Participants by Race..... | 8 |
| Figure 3. Geographical Location of Residence at Time of Burn Injury..... | 9 |
| Figure 4. Distribution of Adults Living With Another Person at the Time of Their Injury..... | 10 |
| Figure 5. Distribution of Children Living With Another Person at the Time of Their Injury..... | 10 |
| Figure 6. Number of Participants by Burn Size Category (% TBSA Burned) | 13 |
| Figure 7. Distribution of Participants by Cause of Injury..... | 15 |
| Figure 8. Number of Participants by Cause of Injury and Age Group..... | 16 |
| Figure 9. Distribution of Participants by Circumstance of Injury..... | 17 |
| Figure 10. Location of Injury Among Participants by Burn Size Category (% TBSA Burned) | 18 |
| Figure 11. Average Length of Acute Care Hospital Stay Among Participants by Year (1993–2016)..... | 19 |
| Figure 12. Number of Participants and Days on Which They Spent on a Ventilator by Age Group..... | 20 |
| Figure 13. Distribution of Participants by Type of Disposition at Hospital Discharge..... | 21 |
| Figure 14. Percentage of Participants With Selected Types of Insurance by Year | 23 |
| Figure 15. Number of Participants With Data at Long-Term Follow-Ups..... | 25 |
| Figure 16. Follow-Ups Completed by Racial/Ethnic Group | 25 |
| Figure 17. Distribution of Types of Surgery Among Participants at All Follow-Ups Combined | 26 |
| Figure 18. Mean Physical Function, Sleep, and Fatigue Scores by Time-point for Adult BMS Participants..... | 29 |
| Figure 19. VR-12/SF12* Mental and Physical Health Scores By Time-point Among Adult BMS Participants and Norm Populations..... | 31 |
| Figure 20. Burn Model Systems Variable and Measure Administration..... | 39 |

List of Tables

| | |
|--|----|
| Table 1. Number and Percentage of Participants by Age Group..... | 7 |
| Table 2. Number and Percentage of Participants by Gender | 8 |
| Table 3. Number and Percentage of Participants by Ethnicity..... | 8 |
| Table 4. Type of Residence at the Time of Burn Injury..... | 9 |
| Table 5. Employment Status of Participants, 18 Years of Age and Older, at the Time of Their Injury | 11 |
| Table 6. School Status of Participants, 5–17 Years of Age, at the Time of Their Injury | 11 |
| Table 7. Pre-Injury Alcohol and Drug Use | 11 |
| Table 8. Pre-Injury Disability | 12 |
| Table 9. Pre-Injury Psychiatric Treatment..... | 12 |
| Table 10. Number and Percentage of Participants by Burn Size Category (% TBSA Burned)..... | 13 |

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

Introduction

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

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

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

The BMS NDSC supports the research teams in the clinical burn centers. It also manages data collected by the BMS centers on more than 6,100 people who have received medical care for burn injuries. The data include a wide range of information—including pre-injury; injury; acute care; rehabilitation; recovery; and outcomes at 6, 12, and 24 months after the burn injury. To be included in the database, the burn injuries of participants must meet several criteria (as of 2015):

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

In 2015, the BMS began a major initiative to collect data every five years after the injury and to collect new psychometrically sound, patient-reported outcome measures. On December 31, 2017, the database contained information for 3,865 adults (18 years of age and older at the time of burn) and 2,235 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](#). Partnerships. Together, these partners help to ensure that NIDILRR-funded research addresses issues that are relevant to people with burn injuries.

Burn Model System Centers

Boston-Harvard Burn Injury Model System (BHBIMS)

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

In addition to contributing to the national database, the BHBIMS conducts a site-specific study. 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

North Texas Burn Rehabilitation Model System (NTBRMS)

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

The NTBRMS was instrumental in establishing the national database and has contributed detailed information on more than 1,500 participants since the BMS began. 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 Coordinator:
Radha Holavanahalli, PhD

Pediatric Burn Injury Rehabilitation Model System

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

Within the Shriners Burn Hospital and University of Texas Medical Branch (UTMB), the Pediatric Burn Injury Rehabilitation Model System contributes to the overall research of the BMS program. In addition to the current longitudinal assessments, UTMB/Shriners BMS Center has a site-specific project, which will assess the relationships and associations between psychosocial health and molecular predictors; habitual physical activity; and insulin sensitivity/resistance. These physiological characterizations, will be evaluated for associations or relationships with psychosocial health, in response to the various anabolic therapies administered to burned patients, and will be explored from admit to 25 years post-burn.

Project Director:

David Herndon, MD

Project Coordinator:

Kathy Epperson, RN, BS

Northwest Regional Burn Model System (NWRBMS)

The NWRBMS is centered in the University of Washington Medicine/Surgery area at Harborview Medical Center. NWRBMS's primary activities include conducting research studies on high-priority topics for people with a burn injury. These topics include patients' employment, rehabilitation, depression, and 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 Coordinator:

Gretchen Carrougher, RN, MN

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

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

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

Project Director:

Dagmar Amtmann, PhD

Project Coordinator:

Kara McMullen, MPH

Summary of Burn Model System Findings 1994–2017

- 6,100 people consented to participate in the BMS database.
- 483 people died before hospital discharge.
- 895 people did not agree to participate in the study.
- 71% of the participants in the database were male.
- 37% of the participants were younger than 18 years of age at the time of their burn injury.
- 73% of the participants were Caucasian; 19% were African-American; and 29% identified as Hispanic.¹
- Mean TBSA burned was 24% across all participants; mean TBSA grafted was 15%.
- 49% 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 28 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 2017, 624 participants went on to inpatient rehabilitation after they were discharged from an acute care unit; average inpatient rehabilitation length of stay for those participants was 24 days (the Pediatric Burn Injury Rehabilitation Model System in Galveston does not have an inpatient rehabilitation unit; therefore these numbers reflect patients from three centers).
- In a study completed in 2007, the participants in the BMS database were found to be representative of the larger National Burn Repository database. The study revealed both internal and external validity for this comparison.² The BMS plans to assess representativeness in another study in 2017.

Cause of Injury³

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

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

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

³ Percentages reported reflect those participants in the database with a known etiology (unknown cause of injury was excluded from this summary). Two percent of participants had “unknown” etiology ($n = 131$).

Demographics

Age Groups and Gender

Figure 1 and Table 1 show the number of burn survivors in the BMS database by age group. Males outnumber females in all categories. People younger than 20 years of age make up 40% 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 gender in the total sample.

Figure 1. Number of Participants by Gender and Age Group

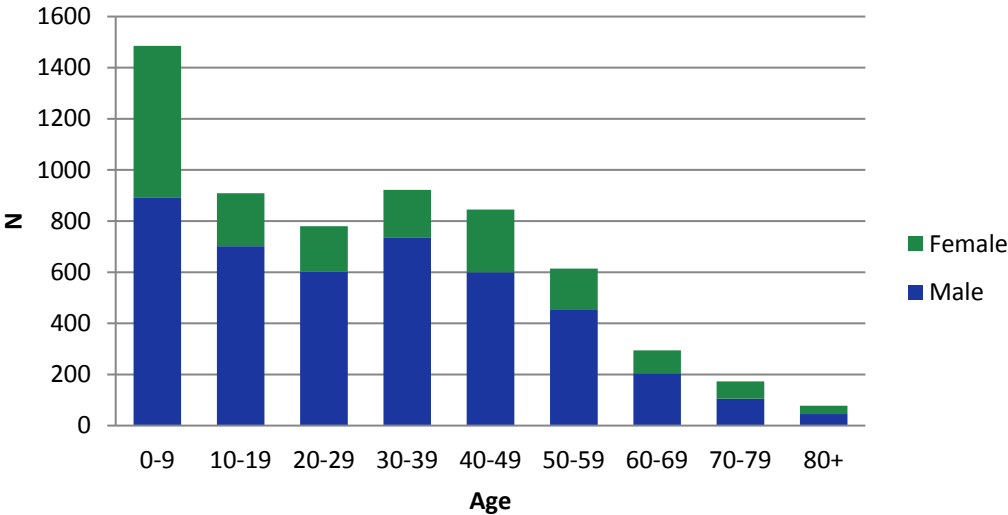


Table 1. Number and Percentage of Participants by Age Group

| Age (Years) | Number of Participants | % |
|-------------|------------------------|-------|
| 0-9 | 1,485 | 25.0% |
| 10-19 | 909 | 15.3% |
| 20-29 | 780 | 13.1% |
| 30-39 | 922 | 15.5% |
| 40-49 | 845 | 14.2% |
| 50-59 | 614 | 10.3% |
| 60-69 | 294 | 5.0% |
| 70-79 | 173 | 2.9% |
| 80+ | 78 | 1.3% |

Table 2. Number and Percentage of Participants by Gender

| Gender | Number of Participants | % |
|--------|------------------------|------|
| Male | 4,339 | 71.1 |
| Female | 1,761 | 28.9 |

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 5.8% of records did not specify ethnicity. Figure 2 is based on the records in which race was specified.

Figure 2. Distribution of Participants by Race

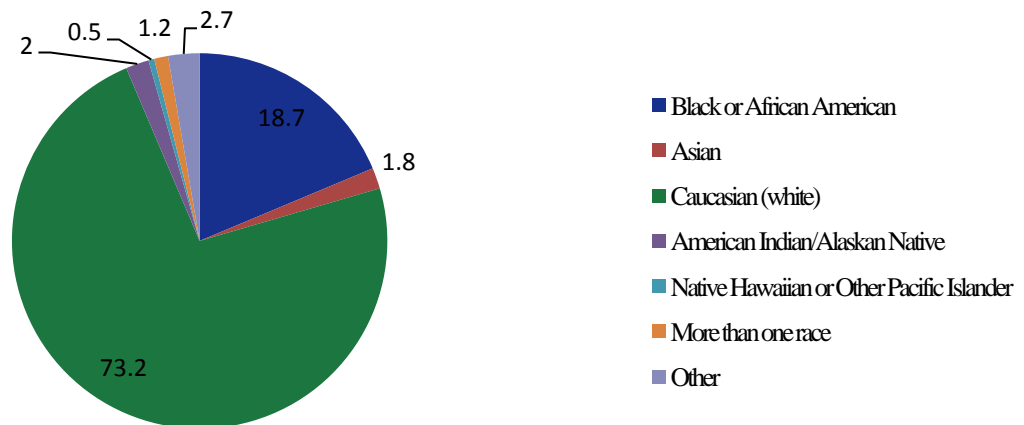


Table 3. Number and Percentage of Participants by Ethnicity

| Ethnicity | Number of Participants | % |
|------------------------|------------------------|------|
| Hispanic or Latino | 1,662 | 28.8 |
| Not Hispanic or Latino | 4,110 | 71.2 |
| Missing/unknown | 328 | |

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 6% of participants had missing or unknown data.

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

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

| Type of Residence | Number of Participants | % |
|-------------------|------------------------|-------|
| House | 4,075 | 66.8% |
| Apartment | 1,041 | 17.1% |
| Mobile home | 393 | 6.4% |
| Other | 115 | 1.9% |
| Homeless | 59 | 1.0% |
| Institution | 24 | 0.4% |
| Missing/unknown | 393 | 6.4% |

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



Living Situation at Time of Injury

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

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

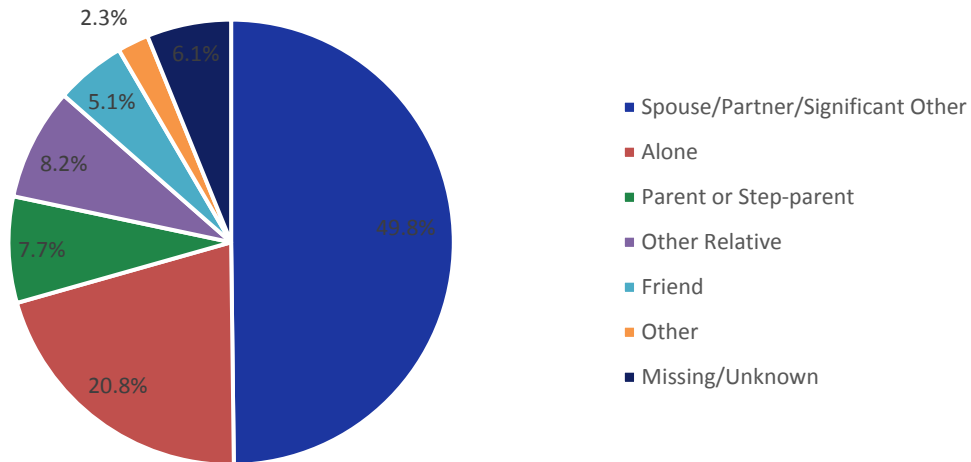
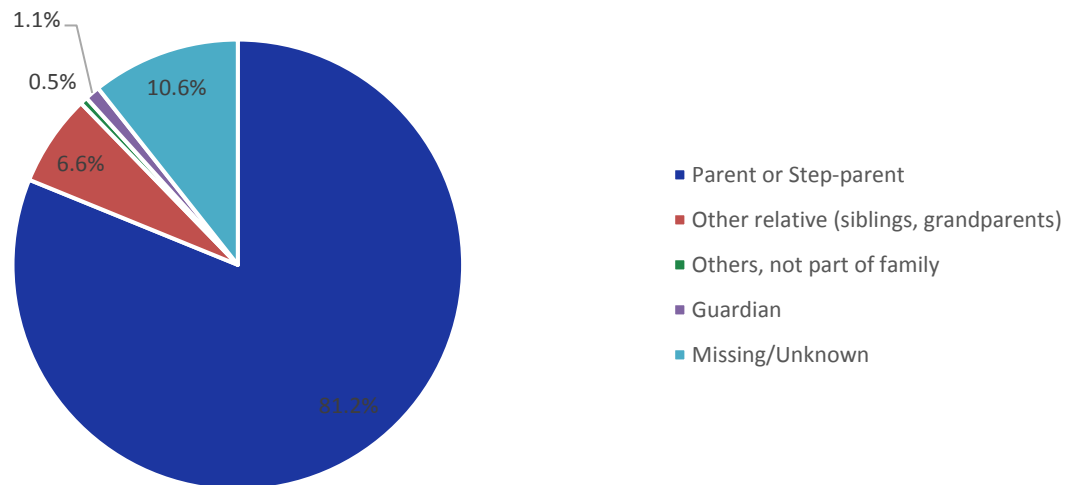


Figure 5. Distribution of Children Living With Another Person at the Time of Their Injury



Employment and School Status at Time of Injury

Table 5 shows the employment status of BMS participants, 18 years of age and older, at the time of their burn injury. Over 2% of participants had missing or unknown data. The majority of adults were employed at the time of their injury. Table 6 shows the school status of children, 5–17 years of age, at the time of their burn injury ($n = 1,224$). 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 | 2,398 | 62.0% |
| Not employed | 941 | 24.3% |
| Retired | 384 | 9.9% |
| Homemaker/caregiver | 45 | 1.2% |
| Volunteer | 7 | 0.2% |
| Missing/unknown | 90 | 2.3% |

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

| School Status | Number of Participants | % |
|-----------------|------------------------|-------|
| In school | 1,021 | 83.4% |
| Not in school | 170 | 13.9% |
| Missing/unknown | 33 | 2.7% |

Adults Reporting Pre-Injury Alcohol Use and Drug Use

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

Table 7. Pre-Injury Alcohol and Drug Use

| Pre-Injury Alcohol and Drug Use | Number of Participants | % |
|--|------------------------|------|
| Alcohol use indicating a potential problem in past 12 months | 538 | 13.9 |
| Drug use indicating a potential problem in past 12 months | 416 | 10.9 |

Participants Reporting Pre-Existing Physical Disability

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

Table 8. Pre-Injury Disability

| Disability | Number of Participants | % |
|--------------------------------|------------------------|-----|
| Pre-injury physical disability | 477 | 7.8 |

Participants Reporting Psychiatric Treatment in the Year Prior to the Injury

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

Table 9. Pre-Injury Psychiatric Treatment

| Psychiatric Treatment | Number of Participants | % |
|---|------------------------|-----|
| Psychiatric treatment in past 12 months | 481 | 7.9 |

Characteristics of Burn Injury

Total Body Surface Area Burned

Figure 6 shows the number of participants in the BMS database by burn size. Among database records that reported burn size, 51.4% of participants had less than 20% TBSA burned. Only 7.9% 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 6. Number of Participants by Burn Size Category (% TBSA Burned)

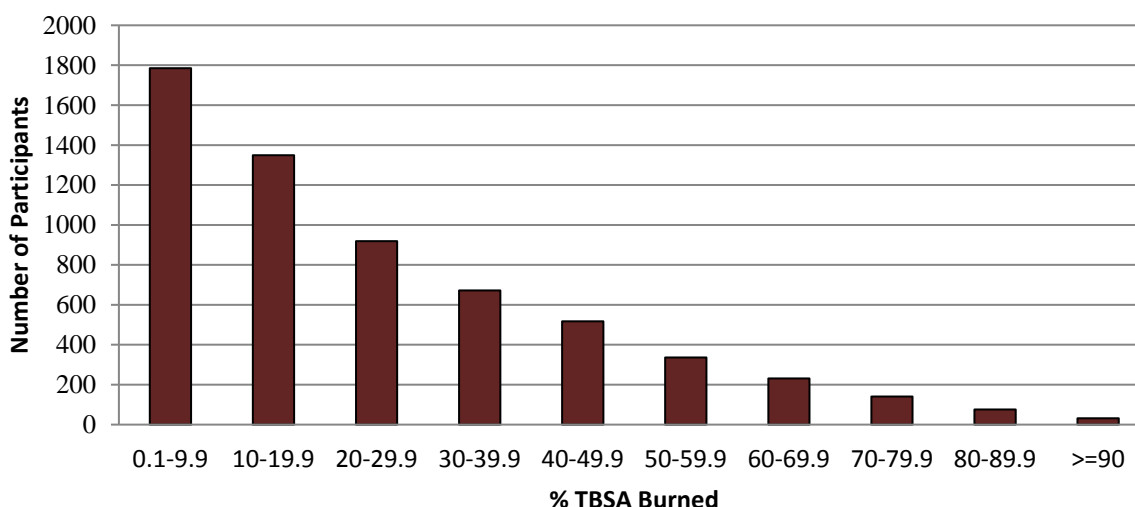


Table 10. Number and Percentage of Participants by Burn Size Category (% TBSA Burned)

| % TBSA Burned | Number of Participants | % |
|-----------------|------------------------|-------|
| 0.1-9.9 | 1,785 | 29.5% |
| 10-19.9 | 1,349 | 22.3% |
| 20-29.9 | 919 | 15.2% |
| 30-39.9 | 672 | 11.1% |
| 40-49.9 | 517 | 8.5% |
| 50-59.9 | 336 | 5.5% |
| 60-69.9 | 231 | 3.8% |
| 70-79.9 | 141 | 2.3% |
| 80-89.9 | 76 | 1.3% |
| ≥90 | 32 | 0.5% |
| Missing/unknown | 42 | 0.69% |
| Total | ta | |

Burn Location on the Body

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

Table 11. Burn Injury Location

| Location | Yes | % | Missing/Unknown | % |
|---------------------------------------|-------|-------|-----------------|------|
| Head/neck burn | 3,388 | 55.5% | 76 | 1.2% |
| Trunk burn | 3,832 | 62.8% | 65 | 1.1% |
| Perineum burn* | 965 | 15.8% | 548 | 9.0% |
| Arm burn (right, left, or bilateral) | 4,269 | 70.0% | 69 | 1.1% |
| Hand burn (right, left, or bilateral) | 4,016 | 65.8% | 79 | 1.3% |
| Leg burn (right, left, or bilateral) | 3,607 | 59.1% | 67 | 1.1% |
| Foot burn (right, left, or bilateral) | 1,937 | 31.8% | 93 | 1.5% |

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

Total Body Surface Area Grafted

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

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

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

| % TBSA Grafted | Number of Participants | % |
|-----------------|------------------------|-------|
| 0–9.9 | 3,083 | 50.5% |
| 10–19.9 | 858 | 14.1% |
| 20–29.9 | 512 | 8.4% |
| 30–39.9 | 324 | 5.3% |
| 40–49.9 | 273 | 4.5% |
| 50–59.9 | 188 | 3.1% |
| 60–69.9 | 110 | 1.8% |
| 70–79.9 | 89 | 1.5% |
| 80–89.9 | 49 | 0.8% |
| ≥90 | 15 | 0.2% |
| Missing/unknown | 599 | 9.8% |
| Total | 6,100 | |

Graft Location

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

Table 13. Burn Graft Location

| Location | Yes | % | Missing/Unknown | % |
|--|-------|-------|-----------------|-------|
| Head/neck graft | 1,152 | 18.9% | 166 | 2.7% |
| Trunk graft | 2,353 | 38.6% | 152 | 2.5% |
| Perineum graft* | 451 | 7.4% | 753 | 12.3% |
| Arm graft (right, left, or bilateral) | 3,058 | 50.1% | 148 | 2.4% |
| Hand graft (right, left, or bilateral) | 2,601 | 42.6% | 169 | 2.8% |
| Leg graft (right, left, or bilateral) | 2,675 | 43.9% | 146 | 2.4% |
| Foot graft (right, left, or bilateral) | 1,351 | 22.1% | 180 | 3.0% |

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

Cause of Injury

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

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

Figure 7. Distribution of Participants by Cause of Injury

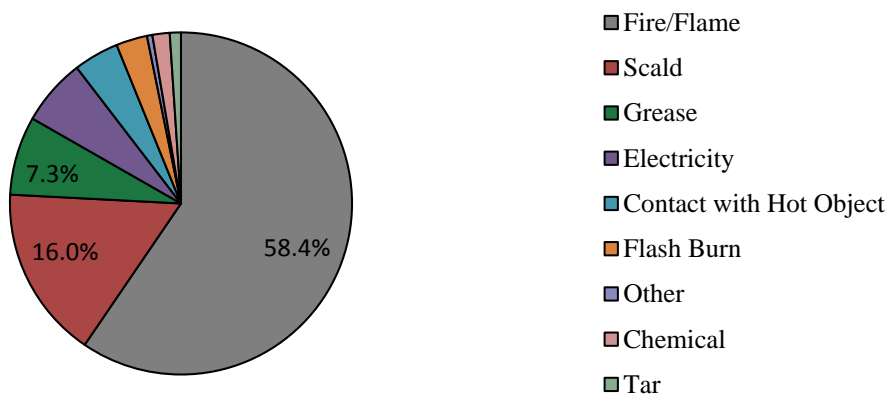
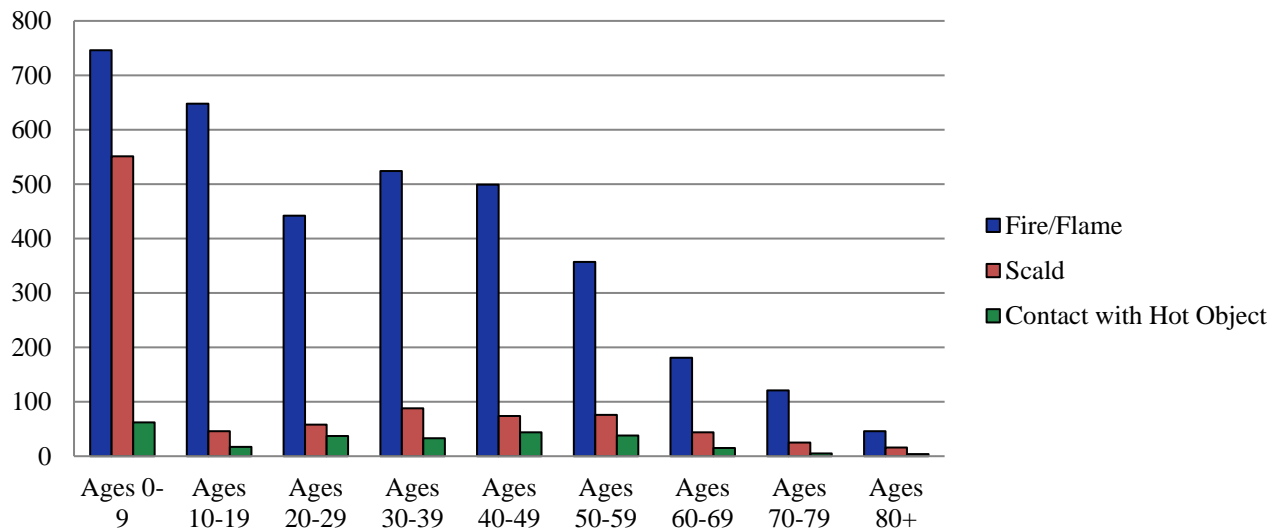


Table 14. Number and Percentage of Participants by Cause of Injury

| Cause of Injury | Number of Participants | % |
|-------------------------|------------------------|-------|
| Fire/Flame | 3,564 | 58.4% |
| Scald | 978 | 16.0% |
| Grease | 448 | 7.3% |
| Electricity | 375 | 6.2% |
| Contact with Hot Object | 255 | 4.2% |
| Flash Burn | 168 | 2.9% |
| Other | 29 | 0.5% |
| Chemical | 98 | 1.6% |
| Tar | 60 | 1.0% |
| Unknown/Missing | 125 | 2.0% |

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



Circumstances and Place of Injury

Table 15 and Figure 9 provide data on the circumstances of injury among participants in the BMS database. Data on the circumstances of injury were unknown for 2.3% of participants. Figure 9 is based on participants whose circumstances of injury were known. The majority of burn injuries in the database were considered nonintentional, 16% of which were related to employment. About 6% of burn injuries were considered intentional.

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

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

| Circumstance of Injury | Number of Participants | % |
|------------------------------------|------------------------|-------|
| Non-intentional non-work related | 3,093 | 50.7% |
| Non-intentional employment related | 969 | 15.9% |
| Non-intentional recreation | 812 | 13.3% |
| Non-intentional unspecified | 719 | 11.8% |
| Suspected assault--domestic | 132 | 2.2% |
| Suspected self-inflicted/suicide | 135 | 2.2% |
| Suspected assault--non-domestic | 80 | 1.3% |
| Suspected arson | 21 | 0.3% |
| Missing/unknown | 139 | 2.3% |

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

Figure 9. Distribution of Participants by Circumstance of Injury

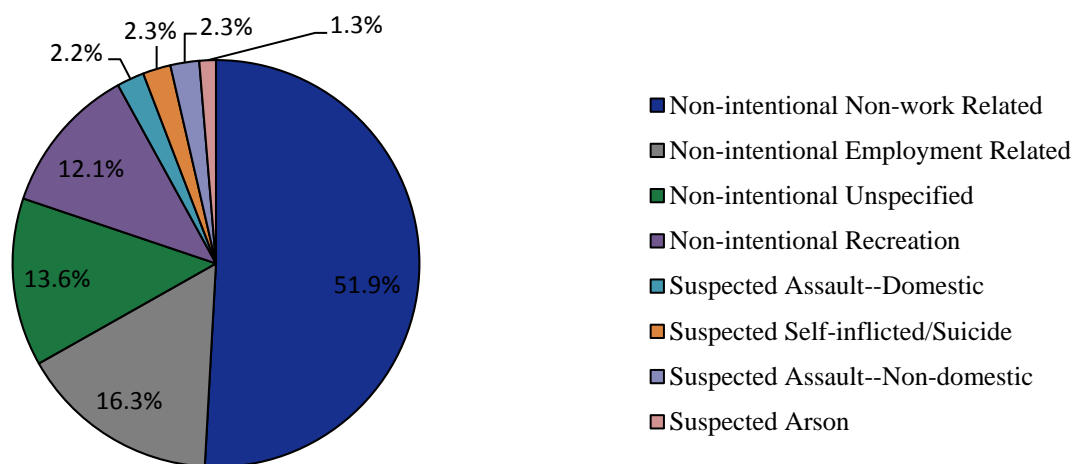
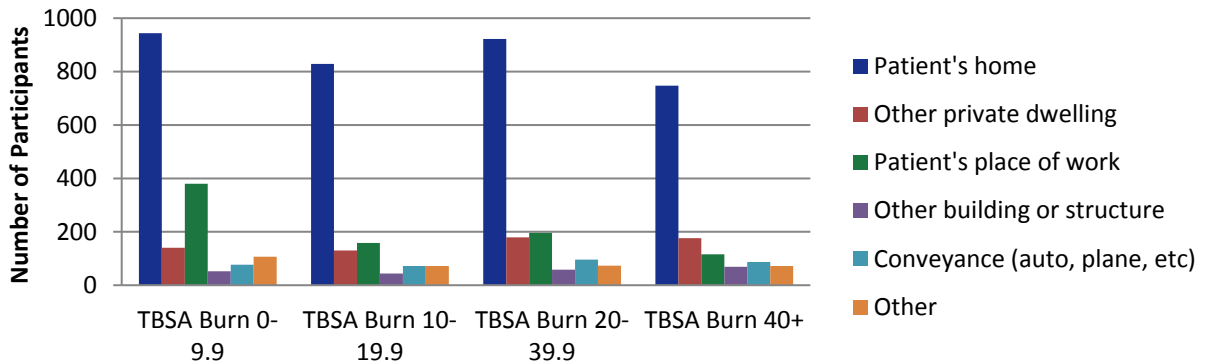


Table 16. Number and Percentage of Participants by Place of Injury

| Place of Injury | Number of Participants | % |
|-----------------|------------------------|-------|
| Closed/Indoors | 3,552 | 61.8% |
| Open/outdoors | 2,363 | 41.1% |
| Missing/unknown | 185 | 3.2% |

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



Inhalation and Other Injuries

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

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

| Type of Injury | Number of Participants | % |
|-------------------------|------------------------|------|
| Inhalation injury | 934 | 15.6 |
| Other injury | 751 | 12.7 |
| Range of motion deficit | 2,905 | 54.7 |

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

| Gender | Inhalation Injury % | Other Injuries% |
|---------|---------------------|-----------------|
| Males | 15.0 | 13.0 |
| Females | 17.2 | 11.8 |

Treatment Before Discharge

Length of Acute Care Hospital Stay

Figure 11 shows the average length of acute care hospital stay at the BMS Center per year among participants in the BMS database. Only 22 records (0.4%) in the database were missing data on the length of hospital stay. Figure 11 is based on available data. From 1993 to 2017, the average length of stay was 27 days. Length of stay varies across years, with no downward or upward trend. Table 19 shows the average length of hospital stay by percent TBSA burned.

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

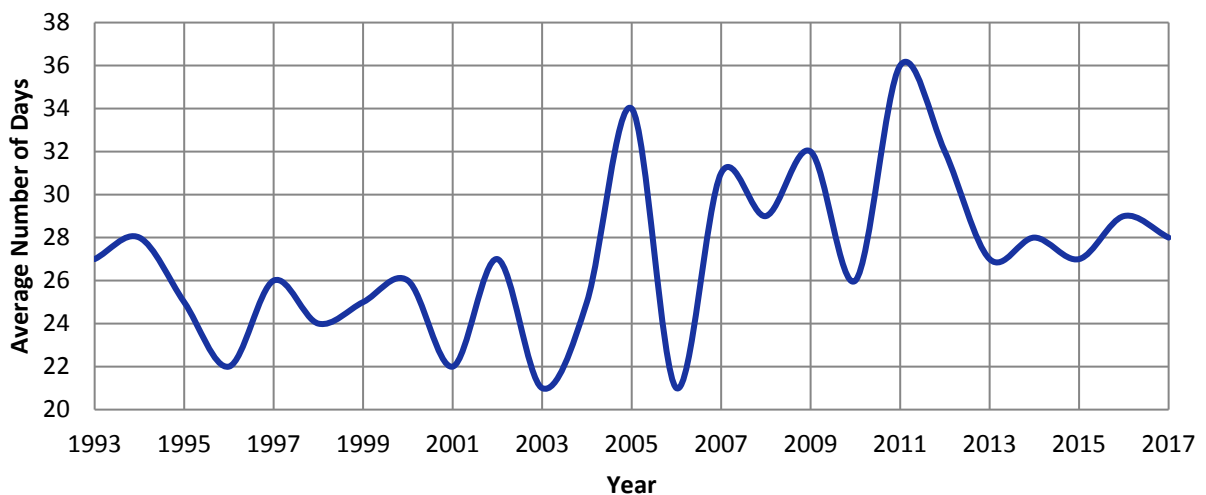


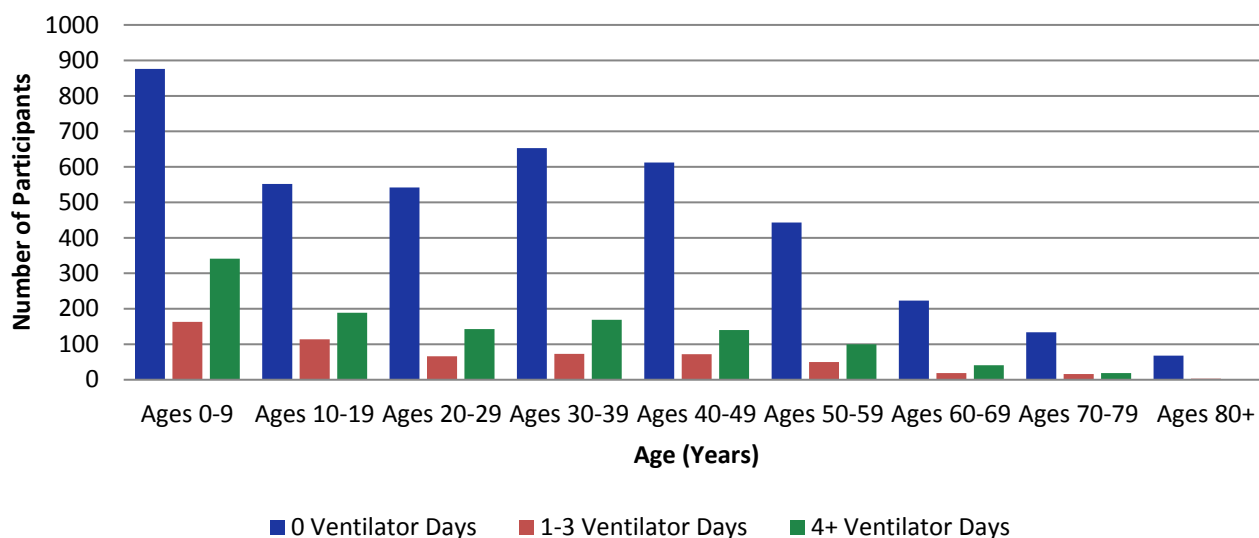
Table 19. Average Length of Acute Care Hospital Stay Among Participants by Burn Size Category (% TBSA Burned)

| % TBSA Burned | Average Length of Hospital Stay (Days) |
|---------------|--|
| 0–9.9 | 14.1 |
| 10–19.9 | 19.4 |
| 20–29.9 | 25.8 |
| 30–39.9 | 31.2 |
| 40–49.9 | 37.6 |
| 50–59.9 | 40.7 |
| 60–69.9 | 51.7 |
| 70–79.9 | 63.5 |
| 80–89.9 | 84.8 |
| ≥90 | 157.8 |

Ventilator Days

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

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



Inpatient Rehabilitation Days

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

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

| Inpatient Rehabilitation Days* | Number of Participants | % |
|--|------------------------|-------|
| Did not go to rehab (0 inpatient rehab days) | 3,653 | 76.0% |
| 1–10 days of rehab | 160 | 3.3% |
| 11–20 days of rehab | 218 | 4.5% |
| ≥21 days of rehab | 242 | 5.0% |
| Missing/unknown | 534 | 11.1% |

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

Hospital Discharge Data

Hospital Disposition

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

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

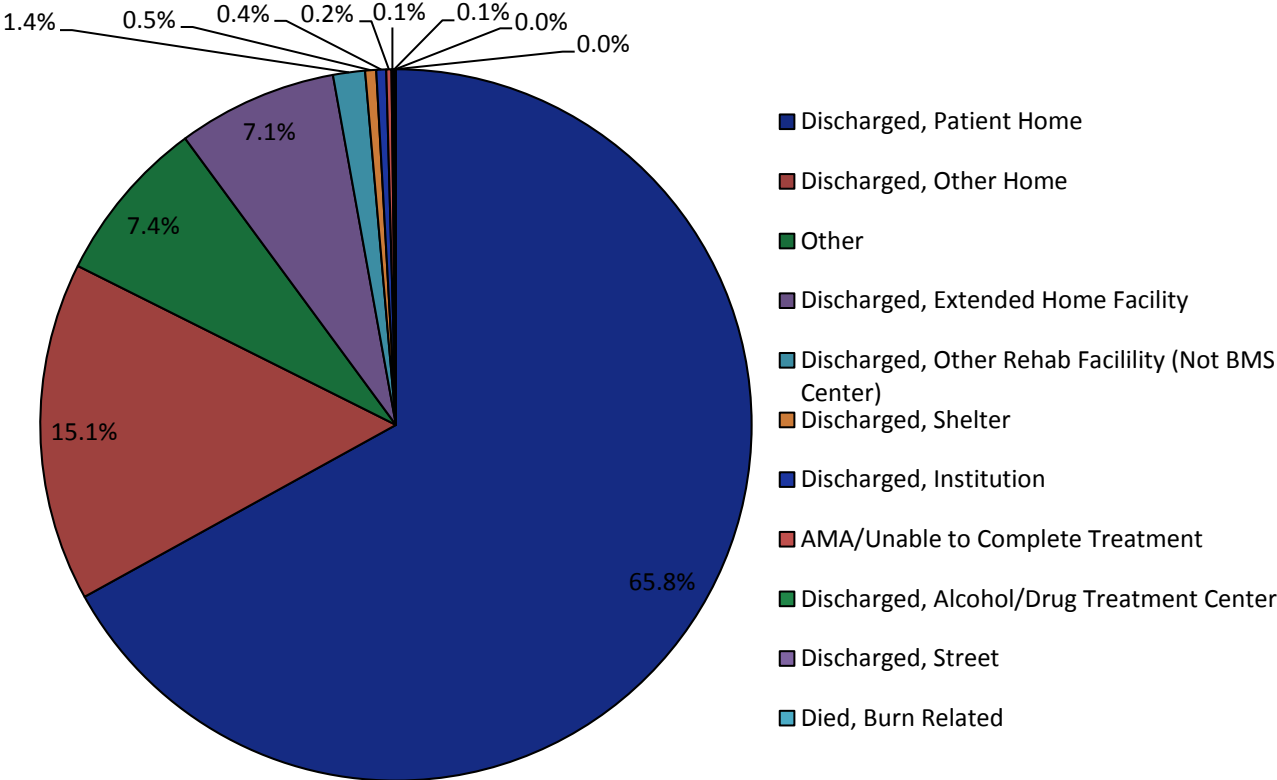


Table 21. Number and Percentage of Participants by Type of Disposition at Hospital Discharge

| Disposition | Number of Participants | % |
|--|------------------------|-------|
| Discharged, patient home | 4,013 | 65.8% |
| Discharged, other home | 923 | 15.1% |
| Other | 451 | 7.4% |
| Discharged, extended home facility | 435 | 7.1% |
| Discharged, other rehab facility (not BMS Center) | 87 | 1.4% |
| Discharged, shelter | 30 | 0.5% |
| Discharged, institution | 27 | 0.4% |
| Unable to complete treatment | 14 | 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 | 108 | 1.8% |

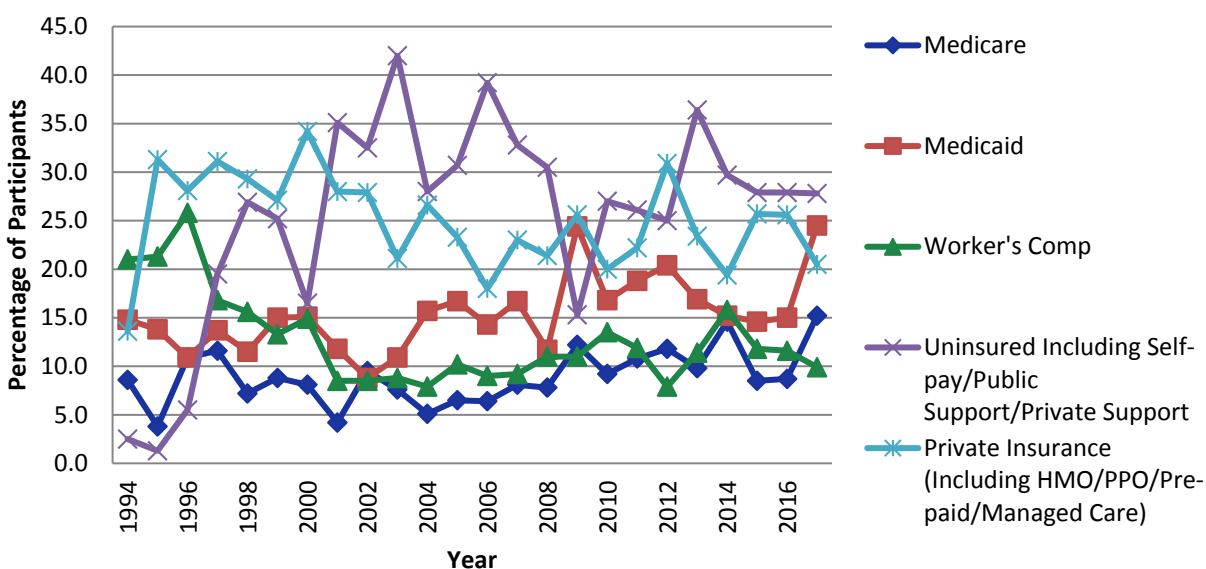
Primary Sponsor of Care at Discharge

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

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

| Primary Sponsor of Care at Discharge | Number of Participants | % |
|--|------------------------|-------|
| Philanthropy or private support | 1,039 | 17.0% |
| Private insurance | 875 | 14.3% |
| Medicaid | 831 | 13.6% |
| Worker's compensation/labor and industries | 628 | 10.3% |
| Other | 527 | 8.6% |
| Health Maintenance Organization (HMO)/Preferred Provider Organization (PPO)/prepaid/managed care | 510 | 8.4% |
| Medicare | 483 | 7.9% |
| Self-pay | 340 | 5.6% |
| Indigent or public support | 137 | 2.2% |
| Champus | 28 | 0.5% |
| Veterans Affairs | 24 | 0.4% |
| Missing/unknown | 678 | 11.1% |

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



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 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 2015). Figure 15 identifies the number of completed follow-ups at longer term time-points (i.e., 5, 10, and 15 years post-burn). Data collection for these time-points began in 2015 and, for some centers, requires the participant to re consent to the study before they provide any follow-up data. Figure 15 shows follow-ups completed by racial/ethnic group and is based on available data.

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

| Follow-Up Status | 6 Months | | 12 Months | | 24 Months | |
|--|------------------------|-------|------------------------|-------|------------------------|-------|
| | Number of Participants | % | Number of Participants | % | Number of Participants | % |
| Data collected/Follow-up Complete | 4,301 | 77.8% | 3,707 | 76.6% | 3113 | 69.9% |
| Death due to burn-related complications | 15 | 0.3% | 12 | 0.3% | 10 | 0.2% |
| Death due to non-burn complications | 25 | 0.5% | 39 | 0.8% | 56 | 1.3% |
| Unable to locate | 362 | 6.6% | 400 | 8.3 | 612 | 13.7% |
| Refused this assessment | 54 | 1.0% | 47 | 1.0% | 85 | 1.9% |
| Unable to test/medically incapable of responding | 15 | 0.3% | 17 | 0.4% | 27 | 0.6% |
| Failed to respond | 690 | 12.5% | 533 | 11 | 467 | 10.5% |
| Did not consent to future assessment/withdrew | 42 | 0.8% | 50 | 1.0% | 56 | 1.3% |
| Incarcerated | 6 | 0.1% | 17 | 0.4% | 20 | 0.5% |
| Still in hospital (not discharged yet) | 7 | 0.1% | 0 | 0.0% | 0 | 0.0% |
| Other | 12 | 0.2% | 20 | 0.4% | 9 | 0.2% |

Figure 15. Number of Participants With Data at Long-Term Follow-Ups

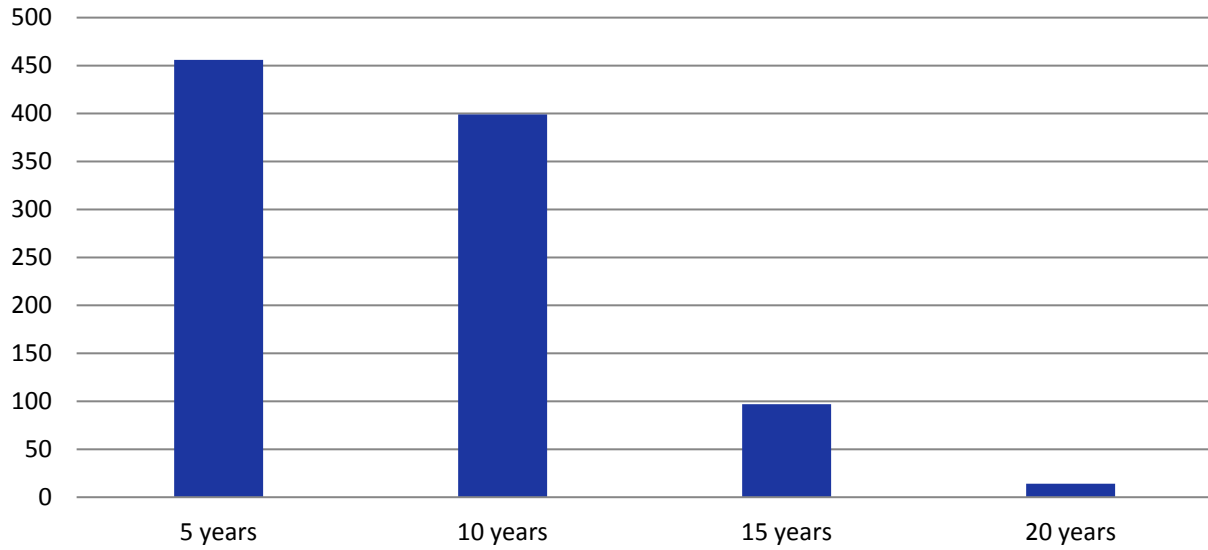
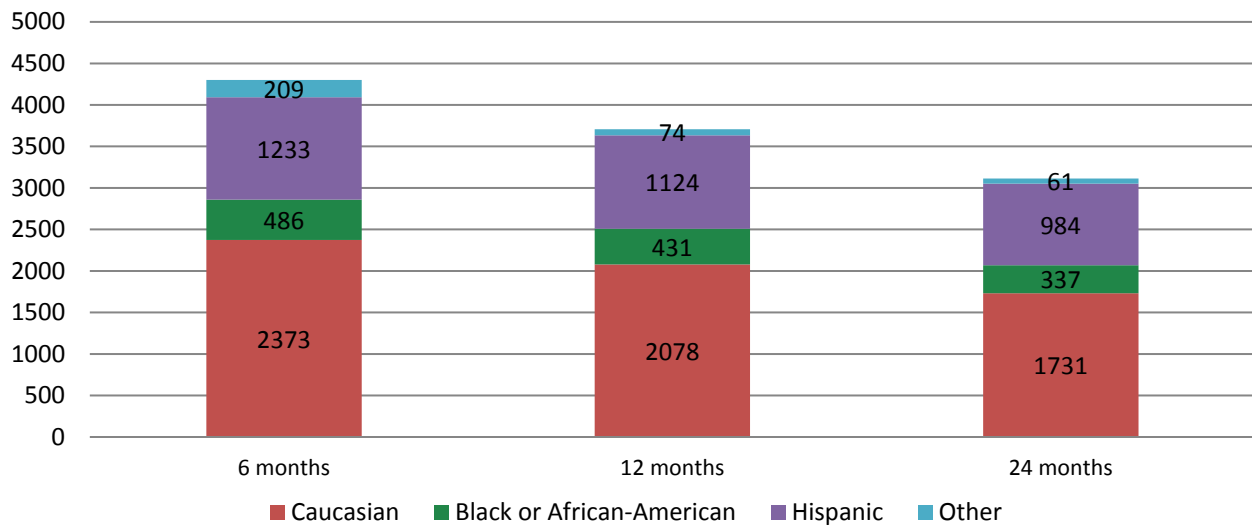


Figure 16. Follow-Ups Completed by Racial/Ethnic Group



Treatment After Discharge

Burn-Related Surgeries and Therapy Use

Table 24 identifies the types of post-discharge surgeries among participants in the BMS database. Table 25 lists the types of therapy (e.g., physical [PT], occupational [OT], and psychological/peer support therapy) at each follow-up. These variables have only been collected since 2009; therefore this data applies to only those participants injured since 2009 ($n = 1,640$). Percentages reflect only available data. Figure 17 displays the distribution of types of surgery across all follow-ups combined.

Table 24. Number and Percentage of Participants by Type of Surgery Since Last Follow-Up

| Type of Surgery Since Last Follow-Up* | 6 Months | | 12 Months | | 24 Months | |
|---|------------------------|------|------------------------|------|------------------------|------|
| | Number of Participants | % | Number of Participants | % | Number of Participants | % |
| Burn-related surgeries since last follow-up | 247 | 17.3 | 297 | 22.3 | 293 | 24.8 |
| Surgery for open wounds** | 83 | | 60 | | 46 | |
| Surgery for joint contractures** | 120 | | 158 | | 155 | |
| Surgery for scar management** | 133 | | 174 | | 197 | |

*Data collection for these variables began in 2009.

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

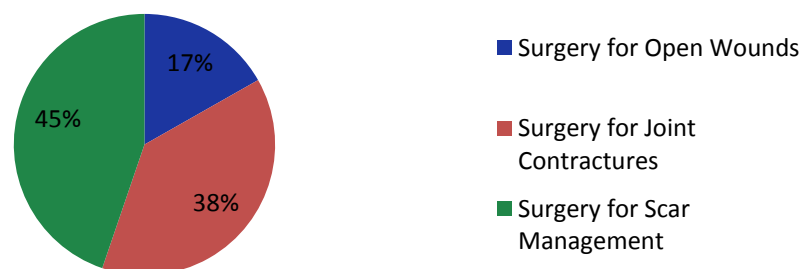
Table 25. Number and Percentage of Participants by Therapy Use Since Last Follow-Up

| Therapy Use Since Last Follow-Up | 6 Months | | 12 Months | | 24 Months | |
|---|------------------------|------|------------------------|------|------------------------|------|
| | Number of Participants | % | Number of Participants | % | Number of Participants | % |
| OT/PT* | 812 | 52.9 | 554 | 38.8 | 341 | 26.8 |
| Psychological or peer support therapy** | 63 | 23.5 | 45 | 20.5 | 37 | 18.0 |

*Data collection for these variables began in 2009.

**Data collection for this variable began in 2015

Figure 17. Distribution of Types of Surgery Among Participants at All Follow-Ups Combined



Physical Outcomes After Burn Injury

Physical Issues in Adults

Table 26 presents data on various physical issues among adults in the BMS database at three time-points. Data on these variables have only been collected since 2015; therefore this data applies to only those participants injured since 2015 (*n* = 359). Percentages reflect participants for whom there is data for these physical issues.

Table 26. Physical Issues in Adults

| Physical Issues* | 6 Months | | 12 Months | | 24 Months | | 5 years | |
|---|----------|-------|-----------|-------|-----------|-------|---------|-------|
| | N | % | N | % | N | % | N | % |
| Hearing loss | 32 | 14.0% | 23 | 12.7% | 26 | 15.0% | 4 | 7.5% |
| Change in voice | 23 | 10.1% | 12 | 6.6% | 23 | 13.3% | 10 | 18.9% |
| Vision problems not corrected by contacts or glasses | 32 | 14.0% | 24 | 13.3% | 15 | 8.7% | 10 | 18.9% |
| Eyelid problems | 14 | 6.1% | 4 | 2.2% | 9 | 5.2% | 5 | 9.4% |
| Excessive tearing of the eyes | 17 | 7.5% | 17 | 9.4% | 8 | 4.6% | 6 | 11.3% |
| Difficulty with memory | 61 | 26.8% | 58 | 32.0% | 43 | 24.9% | 21 | 39.6% |
| Difficulty with thought processing | 46 | 20.2% | 37 | 20.4% | 39 | 22.5% | 17 | 32.1% |
| Numbness, pins and needles or burning sensations in burn scar | 159 | 69.7% | 118 | 65.2% | 84 | 48.6% | 28 | 52.8% |
| Numbness, pins and needles or burning sensations in hands | 108 | 47.4% | 69 | 38.1% | 60 | 34.7% | 23 | 43.4% |
| Numbness, pins and needles or burning sensations in feet | 71 | 31.1% | 54 | 29.8% | 46 | 26.6% | 17 | 32.1% |
| Trouble with balance | 64 | 28.1% | 52 | 28.7% | 48 | 27.7% | 23 | 43.4% |
| Varicose veins | 13 | 5.7% | 11 | 6.1% | 14 | 8.1% | 2 | 3.8% |
| Swollen feet or legs | 56 | 24.6% | 44 | 24.3% | 35 | 20.2% | 14 | 26.4% |
| Swollen hands or arms | 28 | 12.3% | 20 | 11.0% | 15 | 8.7% | 6 | 11.3% |
| Difficulty with breathing when doing regular activities | 2 | 0.9% | 3 | 1.7% | 2 | 1.2% | 2 | 3.8% |
| Skin cancer | 32 | 14.0% | 23 | 12.7% | 26 | 15.0% | 4 | 7.5% |

*Data collection for these variables began in 2015.

Physical Issues in Children

Table 27 presents data on various physical issues among children in the BMS database at three time-points. Data on these variables have only been collected since 2015; therefore this data applies to only those participants injured since 2015 (n= 200). 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 27. Physical Issues in Children

| Problems with... | 6 Months | | 12 Months | | 24 Months | | 5 years | | 10 years | |
|----------------------------------|----------|-------|-----------|-------|-----------|-------|---------|-------|----------|-------|
| | N | % | N | % | N | % | N | % | N | % |
| Seeing | 8 | 6.2% | 15 | 11.3% | 10 | 8.5% | 17 | 23.9% | 24 | 42.9% |
| Hearing | 2 | 1.6% | 2 | 1.5% | 6 | 5.1% | 4 | 5.6% | 8 | 14.3% |
| Learning and understanding | 10 | 7.8% | 10 | 7.5% | 20 | 17.1% | 12 | 16.9% | 6 | 10.7% |
| Controlling emotions or behavior | 43 | 33.3% | 34 | 25.6% | 43 | 36.8% | 18 | 25.4% | 14 | 25.0% |
| Sleeping | 41 | 31.8% | 25 | 18.8% | 19 | 16.2% | 12 | 16.9% | 10 | 17.9% |
| Breathing | 8 | 6.2% | 6 | 4.5% | 6 | 5.1% | 6 | 8.5% | 1 | 1.8% |
| Chronic open skin areas | 24 | 18.6% | 22 | 16.5% | 17 | 14.5% | 7 | 9.9% | 4 | 7.1% |
| Other skin problems | 12 | 9.3% | 7 | 5.3% | 13 | 11.1% | 6 | 8.5% | 2 | 3.6% |

Physical Function, Sleep, and Fatigue among Adults

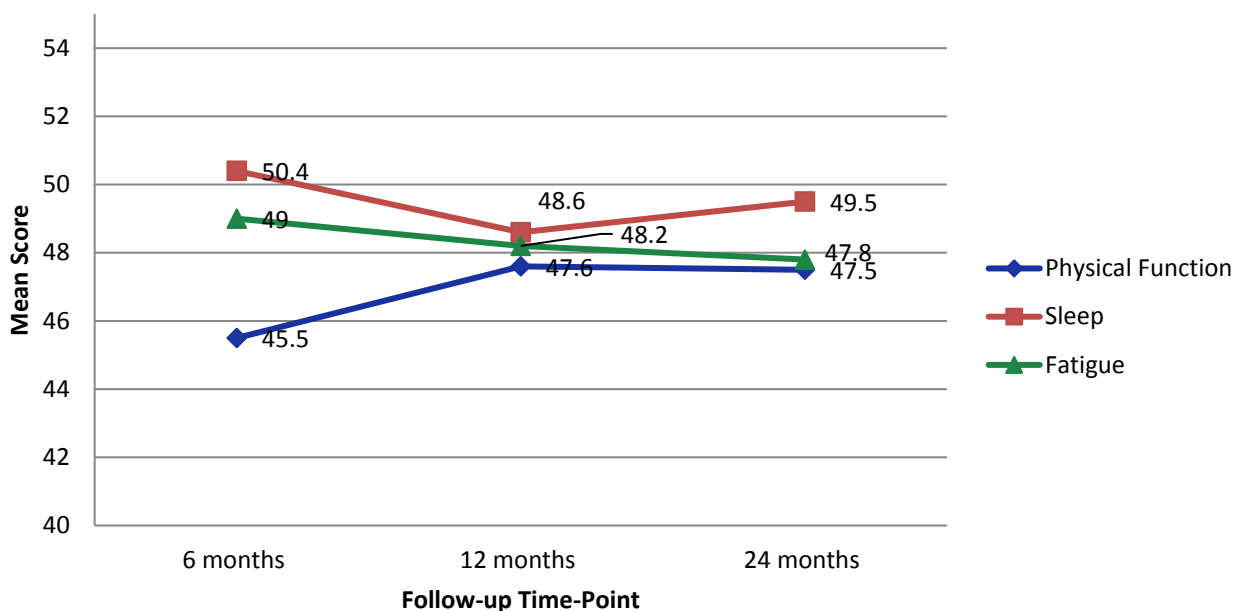
Table 28 presents data on the physical function, sleep, and fatigue scores among adult participants in the BMS database at three time-points. These problems are assessed using the PROMIS 29 scale⁴, which collects data on several areas of functioning and then provides norm scores that can be compared to the general population. The scoring is calculated such that a score of 50 (from a possible range of 0-100) is the general population score. These variables have only been collected since 2015; therefore, these data apply only to those participants injured since 2015 ($n = 359$). Figure 18 shows the trend in mean pain, itch, and sleep problems. Over time, problems with pain or sleep remain relatively constant, while problems with itch trend downward. These are trends in the data as a whole and do not necessarily represent individual participant experience or repeated measures.

Table 28. Mean Physical Function, Sleep, and Fatigue Scores by Time-Point for Adult BMS Participants

| | 6 Months | | 12 Months | | 24 Months | |
|-------------------|-------------|-----|-------------|-----|-------------|-----|
| | Mean (SD) | N | Mean (SD) | N | Mean (SD) | N |
| Physical Function | 45.5 (10.0) | 196 | 47.6 (10.0) | 168 | 47.5 (10.1) | 162 |
| Sleep | 50.4 (10.6) | 200 | 48.6 (10.4) | 170 | 49.5 (10.2) | 160 |
| Fatigue | 49.0 (11.3) | 197 | 48.2 (10.5) | 168 | 47.8 (11.3) | 157 |

*Data collection for these variables began in 2015.

Figure 18. Mean Physical Function, Sleep, and Fatigue Scores by Time-point for Adult BMS Participants



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

Functional Outcomes After Burn Injury

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

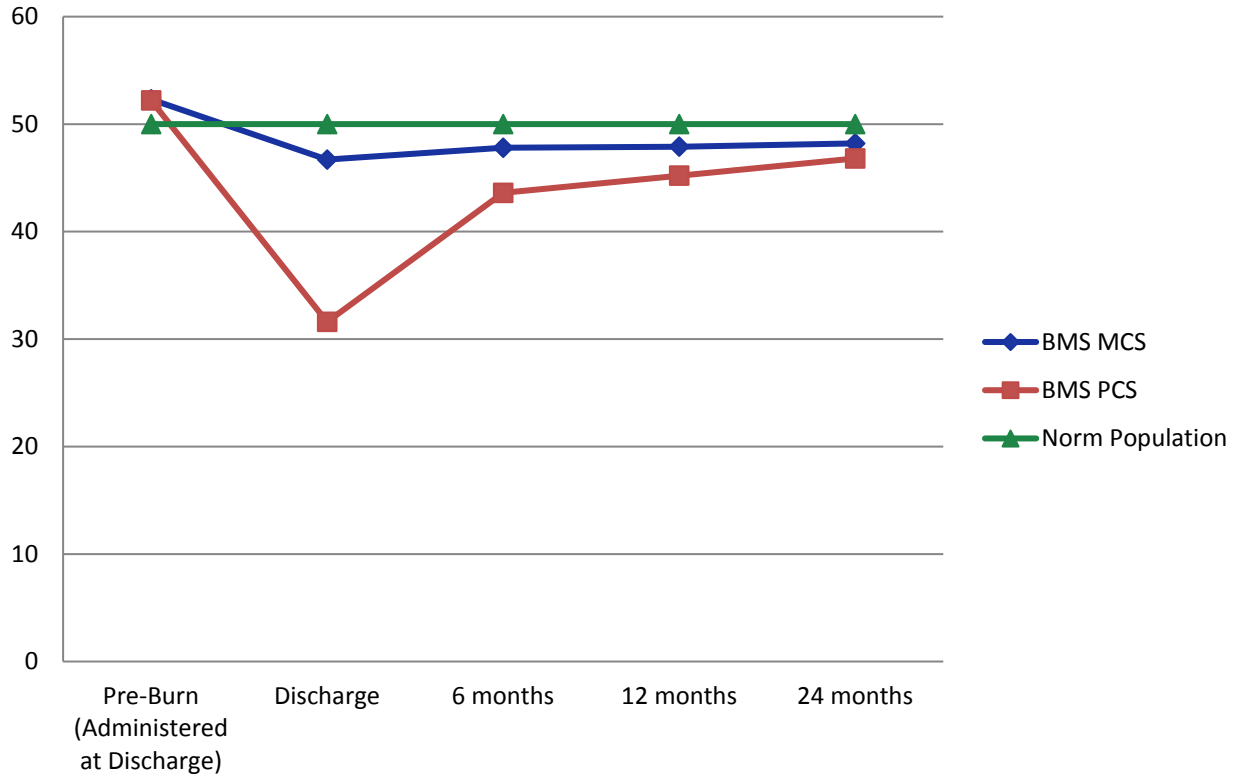
Table 29 presents the mean VR12/SF-12 Mental Health Component (MCS) and Physical Health Component (PCS) scores for adult participants, in the BMS database at each follow-up time-point. The SF12/VR-12 are sets of questions that clinicians ask patients to understand how people are doing physically and mentally. Possible scores range from 0 to 100, with higher scores indicating better health. The average mental and physical health score across the U.S. population is 50.0. The BMS moved from the SF-12 to the VR-12 in 2015. The data presented here presents MCS and PCS scores as collected by both the SF-12 and the VR-12. For comparison purposes, Figure 19 presents the BMS and norm (or general) population scores across time.

Table 29. Mean SF12/VR12 Scores Among Adult BMS Participants

| Mean VR-12/SF12* Scores, Adults | Pre-Burn (Administered at Discharge) | | Discharge | | 6 Months | | 12 Months | | 24 Months | |
|---------------------------------|--------------------------------------|-------|-----------|-------|----------|-------|-----------|-------|-----------|-------|
| | Mean | N | Mean | N | Mean | N | Mean | N | Mean | N |
| MCS | 52.3 | 2,253 | 46.7 | 2,215 | 47.8 | 1,580 | 47.9 | 1,462 | 48.2 | 1,270 |
| PCS | 52.2 | 2,253 | 31.6 | 2,215 | 43.6 | 1,580 | 45.2 | 1,462 | 46.8 | 1,270 |

*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 19. 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 30 presents data on the post-burn injury employment status at follow-up of adults, 18 years of age and older, in the BMS database ($n = 3,865$), and is based on only available data. Table 31 presents data on the post-injury school status at follow-up of children, 5–17 years of age, in the BMS database ($n = 1,224$). Like employment status for adults, data on school status among children have not been collected during the entire span of the BMS. Therefore, Table 31 is based on only available data.

Table 30. 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 | 1,090 | 32.3% | 1,131 | 37.4% | 1,044 | 41.2% |
| Not Working | 1,754 | 51.9% | 1,373 | 45.4% | 1,064 | 41.9% |
| Homemaker/Caregiver | 28 | 0.8% | 31 | 1.0% | 28 | 1.1% |
| Volunteer | 16 | 0.5% | 7 | 0.2% | 9 | 0.4% |
| Retired | 279 | 8.3% | 261 | 8.6% | 217 | 8.6% |
| Not applicable | 210 | 6.2% | 218 | 7.2% | 175 | 6.9% |

*Data collection for these variables began in 2009.

Table 31. 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 | 477 | 81.4% | 488 | 81.6% | 466 | 81.3% |
| Not school | 109 | 21.0% | 110 | 21.3% | 107 | 21.7% |

*Data collection for these variables began in 2009.

New Burn Model System Data Collection

The Burn Model System started collecting data on new variables and measures in 2015, using psychometrically sound, standardized instruments, such as those developed by the PROMIS initiative, which is funded by the National Institutes of Health (NIH). Table 32 describes the instruments and what they measure (i.e., domains) and provides additional information.

Table 32. Summary of New BMS Data Collection Instruments and Measures

| Measure | Time-Point Administered | New, Dropped, or Previously Administered? | Age Group (Years) Administered To | BMS or Standardized Measure? | Number of Items in Measure |
|--|---|---|---|------------------------------|----------------------------|
| Domain: Demographics (including income, marital status, living situation, work status, school status, etc.) | | | | | |
| Demographics | Discharge and all follow-ups | Some items are new, such as household income. Some have been previously collected, such as living situation and work status. | Proxy (ages 0–17); self-report (ages ≥13) | BMS | 25 |
| Domain: Burn Injury Information | | | | | |
| Medical Record Abstraction Form | Discharge | Some items are new, such as MRSA presence/absence. Some have been previously collected, such as etiology of injury and disposition. | All ages | BMS | 45 |
| Burn Injury Follow-Up | All follow-up points, not pre-burn (administered at discharge) or discharge | Some items are new, such as the ability to drive. Some have been previously collected, such as physical or psychological therapy. | Proxy (ages 0–17); self-report (ages ≥13) | BMS | 15 |

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

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

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

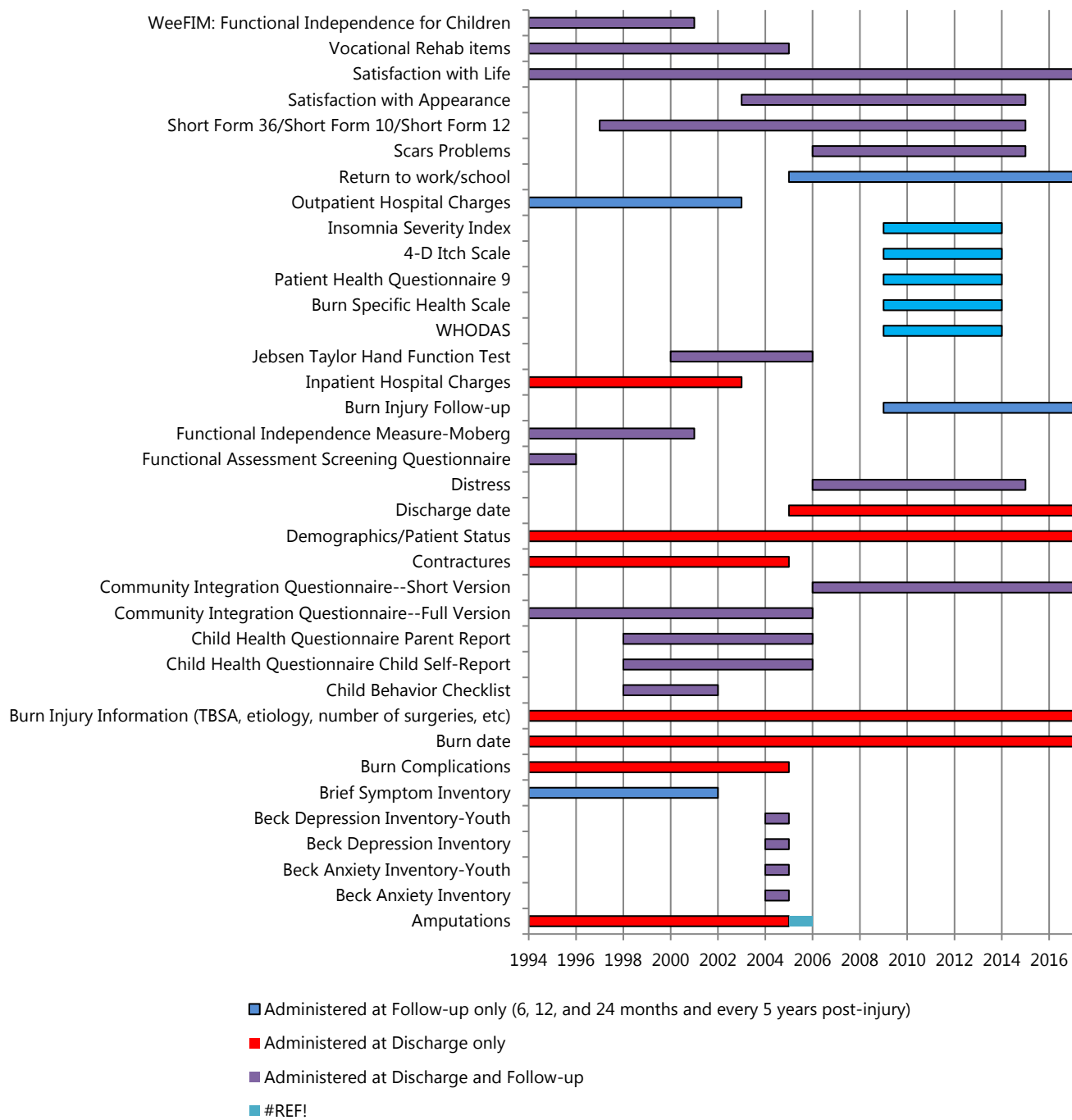
| Measure | Time-Point Administered | New, Dropped, or Previously Administered? | Age Group (Years) Administered To | BMS or Standardized Measure? | Number of Items in Measure |
|---|---|---|---|--|--|
| Domain: Drug/Alcohol/Medication Use | | | | | |
| CAGE Alcohol/Drug Use | Discharge and all follow-ups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

| Measure | Time-Point Administered | New, Dropped, or Previously Administered? | Age Group (Years) Administered To | BMS or Standardized Measure? | Number of Items in Measure |
|---|---|---|--|------------------------------|----------------------------|
| Pediatric Evaluation of Disability Inventory—Mobility | All follow-ups, not pre-burn (administered at discharge) or discharge | New | Proxy (ages 0–7) | Standardized | 5 |
| Domain: Satisfaction With Life/Positive Affect | | | | | |
| NIH TB General Life Satisfaction | All follow-ups, not pre-burn (administered at discharge) or discharge | New | Proxy (ages 3–17); self-report (ages 8–17) | Standardized | 4 |
| 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 20 is a timeline representing what data have been collected, and when.

Figure 20. Burn Model Systems Variable and Measure Administration



Timeline created by the Boston-Harvard Burn Model System Center & the Burn Model Systems National Data and Statistical Center

Using the Burn Model System National Database

The BMS national database welcomes the use of the data by external researchers who share our goal of improving the lives of burn survivors. Anyone from the scientific community who wishes to use data from the BMS national database can use this database.

How Do You Request Data?

The following procedures have been designed to be simple, invite participation by external researchers, and maintain the integrity of the data use and confidentiality of the participants.

1. Complete a Data Request and Use Agreement Form, available at <http://burndata.washington.edu/about-database> (under the heading "For Researchers Interested in the Data").
2. Email the completed form to the BMS National Data and Statistical Center (NDSC) at burndata@uw.edu.
3. The BMS NDSC will share the form with the BMS project directors for their review
4. BMS project directors review for principal investigator (PI) affiliation, scientific purpose, and scientific overlap with existing approved projects.
5. BMS project directors will have 10 working days to provide comments; the NIDILRR BMS program manager will consider feedback from the BMS NDSC and BMS project directors when making a final decision regarding approval of the proposal.
6. After approval, the PI will work with the BMS NDSC to specify the variables to be included so an appropriate de-identified dataset can be released to the PI.
7. Applicants have an option to propose or request a BMS researcher as a collaborator/consultant who is familiar with the data and the ways in which they are collected.

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