Burn Model System Summary Report

1993–2014

This report contains information, tables, and figures about the data contained in the Burn Model System National Database, collected from 1993–2014. The Burn Model System (BMS) is funded by the National Institute for Disability and Rehabilitation Research. This report was produced by the BMS National Data and Statistical Center.



Table of Contents

Introduction	1
Burn Model System Centers	2
Boston-Harvard Burn Injury Model System (BHBIMS)	2
North Texas Burn Rehabilitation Model System (NTBRMS)	2
Pediatric Burn Injury Rehabilitation Model System	3
Northwest Regional Burn Model System (NWRBMS)	3
Burn Model System National Data and Statistical Center (BMS NDSC)	4
Summary of Burn Model System Findings 1993–2014	5
Cause of Injury	5
Demographics	6
Age Groups and Gender	6
Ethnicity	7
Residence and Geographical Location at Time of Injury	8
Living Situation at Time of Injury	9
Employment and School Status at Time of Injury	
Participants Reporting Pre-Injury Alcohol Use and Drug Use	
Participants Reporting Pre-Existing Physical Disability	
Participants Reporting Psychiatric Treatment in the Year Prior to Injury	
Characteristics of Burn Injury	12
Total Body Surface Area Burned	
Burn Location on the Body	
Total Body Surface Area Grafted	
Graft Location	14
Cause of Injury	14
Circumstances and Place of Injury	16
Inhalation and Other Injuries	
Treatment Before Discharge	19
Length of Acute Care Hospital Stay	19
Ventilator Days	
Inpatient Rehabilitation Days	
Hospital Discharge Data	21
Hospital Disposition	21
Primary Sponsor of Care at Discharge	
Treatment After Discharge	24
Burn-Related Surgeries and Therapy Use	24
Medical Outcomes After Burn Injury	25
Scar Problems	25
Pain, Itch, and Sleep Problems	25
Functional Outcomes After Burn Injury	27
Short Form 12 and 10 Mental and Physical Health Scores	27
Social Outcomes After Burn Injury	29
Employment Status and School Status	

Long-Term Follow-Up Project	30
Long-Term Outcomes After Burn Injury	30
Physical and Mental Health Scores at 5 and 10 Years After Injury (Measured With the SF12)	30
Depression at 5 and 10 Years After Injury (Measured With the PHQ-9)	30
Itch at 5 and 10 Years After Injury	31
Archived Burn Model System Data	32
Using the Burn Model System National Database	33
How Do You Request Data?	33

List of Figures

Figure 1. Age and Gender	6
-igure 2. Ethnicity of Participants	7
-igure 3. Geographical Location of Residence at Time of Injury	8
-igure 4. Living With Another Person at Time of Injury: Adult	9
-igure 5. Living With Another Person at Time of Injury: Child	9
-igure 6. Burn Size Categories (% TBSA Burned)	12
-igure 7. Cause of Injury	15
-igure 8. Cause of Burn by Age Group	16
-igure 9. Circumstances of Injury	17
-igure 10. Location of Injury by Burn Size Category	18
-igure 11. Length of Acute Care Hospital Stay by Year	19
-igure 12. Days on Ventilator by Age Group	20
-igure 13. Hospital Discharge	21
igure 14. Percentage of Participants With Selected Insurance Type by Year	23
Figure 15. Proportion of Types of Surgery at All Follow-Up Points	24
igure 16. Mean Pain, Itch, and Sleep Problems Over Time for Those Participants Reporting a 1 or High	ıer
on the NRS	26
Figure 17. SF12* Scores Over Time	28
-igure 18. Burn Model Systems Variable and Measure Administration	32

List of Tables

Table 1. Gender by Age Category	6
Table 2. Number of Cases by Gender	7
Table 3. Ethnicity of Participants	7
Table 4. Residence at Time of Burn	8
Table 5. Employment at Time of Injury for Participants, 18 Years Old and Older	10
Table 6. School Status at Time of Injury for Participants 5–17 Years of Age	10
Table 7. Pre-Injury Alcohol and Drug Use	10
Table 8. Pre-Injury Disability	11
Table 9. Psychiatric Treatment Pre-Burn	11
Table 10. Percentage of Total Body Surface Area Burned (TBSA)	12

Table 11. Burn Injury Location	13
Table 12. Percentage of Total Body Surface Area Grafted	13
Table 13. Burn Graft Location	14
Table 14. Cause of Injury	15
Table 15. Circumstances of Injury	
Table 16. Place of Injury	17
Table 17. Inhalation and Other Injuries, and Range of Motion Deficits	
Table 18. Inhalation and Other Injuries by Gender	
Table 19. Average Length of Hospital Stay by TBSA Burn Category	
Table 20. Number of Inpatient Rehabilitation Days	20
Table 21. Disposition	21
Table 22. Primary Sponsor of Care at Discharge	
Table 23. Surgeries Since Last Interview	24
Table 24. Therapy Use Since Last Interview	24
Table 25. Scar Problems	25
Table 26. Pain, Itch, and Sleep Problems	25
Table 27. Percentage of Participants With No Pain, Itch, and Sleep Problems	
Table 28. Mean SF12 Scores, Participants Ages 14 and Over	27
Table 29. Mean SF10 Scores, Participants Ages 0–13	27
Table 30. Employment Status After Burn Injury, Participants 18 Years of Age and Older	29
Table 31. School Status After Burn Injury, Participants 5–17 Years of Age	29
Table 32. Mean SF12 Scores	
Table 33. PHQ-9 Depression Categories	
Table 34. Itch at Long-Term Follow-Up	31

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 1993 with funding from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, to improve, through research, care and outcomes for individuals with burn injuries. The BMS research programs are housed within clinical burn centers that provide a coordinated and multidisciplinary system of rehabilitation care including emergency medical, acute medical, postacute, and long-term follow-up services. In addition to these activities, with their NIDRR funding, each BMS center conducts research and contributes follow-up data to the BMS National Data and Statistical Center (NDSC). The four BMS centers at present 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 include 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 NIDRR-funded BMS NDSC supports the research efforts of the BMS research teams within the clinical burn centers. The BMS NDSC also manages data collected by the BMS centers. The data include information on the course of recovery and outcomes of individuals who received medical care for burn injuries. The BMS database has information on more than 5,000 individuals with burn injuries. Data include information on individuals pre-injury, their injuries, acute care, rehabilitation, and outcomes at 6, 12, and 24 months after burn injury. Inclusion criteria (as of 2014) are: (a) >10% total body surface area burn (TBSA), >65 years of age and with burn surgery for wound closure; (b) >20% TBSA, 0–64 years of age and with burn surgery for wound closure; (d) hand burn and/or face burn and/or feet burn with burn surgery for wound closure. On December 31, 2014, the database contained information about 3,496 adults (ages 18 and older) and 2,023 children (under age 18).

The BMS program disseminates evidence-based information to patients, family members, health care providers, educators, policymakers, and the general public. BMS centers provide information in various 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 NIDRR-funded Model Systems Knowledge Translation Center to promote adoption of research findings by rehabilitation professionals, policymakers, and persons with burn injuries and their family members. Examples of site-specific projects include research related to long-term survivors' needs, efficacy of innovative exercise programs, children with acute stress disorder (ASD) and/or post-traumatic stress disorder (PTSD), and biomechanical properties of burn scars.

The BMS program has established partnerships that serve to increase the overall impact of research, information dissemination, and training of clinicians, researchers, and policy makers. Current collaborations include partnerships with the <u>American Burn Association (ABA)</u> and the <u>Phoenix Society</u> to ensure that NIDRR-funded research addresses issues relevant to persons with burn injuries.

Burn Model System Centers

Boston-Harvard Burn Injury Model System (BHBIMS)

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. BH-BIMS is a collaborative research effort between Spaulding Rehabilitation Hospital, Massachusetts General Hospital and 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 BH-BIMS conducts a site-specific study, Effects of tDCS on Chronic Pain and Itch Following Burn Injury. This study is investigating a noninvasive method of brain stimulation, Transcranial Direct Current Stimulation (tDCS), for the relief of chronic pain and itch due to burn injury.

Project Director: Jeffrey Schneider, MD Project Coordinator: Lynne Friedlander, MEd

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 North Texas Burn Rehabilitation Model System (NTBRMS), housed within these hospitals, is a research team comprising diverse staff.

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

Project Director: Karen Kowalske, MD Project Coordinator: Radha Holavanahalli, PhD

Pediatric Burn Injury Rehabilitation Model System

Shriners Burns Hospital– Galveston, Texas, has worked for more than 40 years to develop new techniques to improve the outcome 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 outcome in patients. Shriners has a strong history of conducting excellent research that translates into providing high-quality care to improve physical, functional, and psychological outcomes after burn injury.

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

Project Director: David Herndon, MD Project Coordinator: Kathy Epperson, RN, BS

Northwest Regional Burn Model System (NWRBMS)

The Northwest Regional Burn Model System (NWRBMS) is centered within the University of Washington Medicine/Surgery area at Harborview Medical Center. NWRBMS's primary activities include conducting research studies on high-priority topics for people with a burn injury. These topics include: patients' employment, rehabilitation, depression, and postburn itching as well as providing research-based education and training to professionals and consumers.

In addition to contributing to the national longitudinal database, the NWRBMS is establishing a Web-based dissemination platform to provide education regarding 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 Worker's Compensation and vocational rehabilitation agencies. The NWRBMS is also conducting a prospective randomized trial aimed at reducing pain and itch by using hypnosis.

Project Director: Nicole Gibran, MD Project Coordinator: Gretchen Carrougher, RN, MN

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

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

Specifically, the NDSC: (a)maintains the national longitudinal database (BMS Database) for data submitted by each of the <u>Burn Model Systems Centers</u> (BMS centers); (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 <u>National Data and</u> <u>Statistical Center for Traumatic Brain Injury Model Systems</u>, the <u>National Data and Statistical Center for</u> <u>Spinal Cord Injury Model Systems</u>, the <u>Model Systems Knowledge Translation Center</u> (MSKTC), and the <u>American Burn Association;</u> (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 1993–2014

- 5,519 people consented to participate in the BMS longitudinal database
- 448 people died before hospital discharge
- 764 people did not agree to participate the study
- 72% of the participants in the database were male
- 37% of the participants were under the age of 18 at the time of burn injury
- 54% of participants were Caucasian; 14% were African-American, and 27% were Hispanic
- Mean total body surface area burned was 24.0% across all cases; mean total body surface area grafted was 15.2%
- 44% of the cases included had total body surface area burned over 20%
- Length of acute care hospital stay was on average 30.2 days for participants under the age of 18
- Length of stay averaged 28.5 days for adults ages 18–30, 26.5 for adults ages 31–45, 30.4 for adults ages 46–64, 26.1 for adults ages 65–74, and 28.4 for adults aged 75 and older
- 663 participants between 1993 and 2014 went on to inpatient rehabilitation after they were discharged from the acute care unit; average inpatient rehabilitation length of stay for those participants was 25 days (the Pediatric Burn Injury Rehabilitation Model System in Galveston does not have an inpatient rehabilitation unit; therefore these numbers reflect patients from all centers except the one in Galveston)
- The participants in the BMS database were found to be representative of the larger National Burn Repository database, with both internal and external validity shown in this comparison¹

Cause of Injury²

- 60%: Fire/flame
- 16%: Scald
- 7%: Grease
- 6%: Electrical
- 4%: Contact with hot object
- 3%: Flash
- 2%: Chemical

¹ 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.

² Percentages reported reflect those cases in the database with a known etiology (unknown cause of injury was excluded from this summary). One percent of cases had "unknown" etiology (n = 58).

Demographics

Age Groups and Gender

Figure 1 and Table 1 show the number of burn survivors by age group. Males outnumber females in all categories. People aged less than 20 make up 39% of all participants. The most prevalent age group is ages 20 – 60, accounting for greater than 52% of all patients. Table 2 describes the breakdown of gender in the total sample.



Figure 1. Age and Gender

Age in Years	Male	%	Female	%
0–9	806	60.0	538	40.0
10–19	644	77.7	185	22.3
20–29	557	78.3	154	21.7
30–39	684	80.0	171	20.0
40–49	556	71.4	223	28.6
50–59	392	74.4	135	25.6
60–69	181	71.3	73	28.7
70–79	87	59.2	60	40.8
80+	43	60.3	30	39.7

Table 1. Gender by Age Category

Table 2. Number of Cases by Gender

Gender	Number of Cases	%
Male	3,950	71.6
Female	1,569	28.4

Ethnicity

Figure 2 and Table 3 show the breakdown of burn survivors in the BMS sample by ethnicity. The table shows that 1.0% of records did not specify race. The figure is based on those records in which race was specified (i.e., it is based on nonmissing data).

Figure 2. Ethnicity of Participants



Table 3. Ethnicity of Participants

Ethnicity of Participants	Number of Cases	%
White, non-Hispanic	2,956	53.7
Hispanic	1,469	26.6
Black, non-Hispanic	783	14.2
Native American	80	1.5
Asian	77	1.4
Multiracial	51	0.9
Other	30	0.6
Pacific Islander	19	0.3
Missing/unknown	54	1.0

Page | 7

Residence and Geographical Location at Time of Injury

Table 4 describes the residence at the time of injury for participants in the BMS database. 4.4% of cases had unknown or missing data for this data point. Figure 3 is a map of the location of residence at time of burn for the sample, with areas more highly concentrated with BMS participants represented by larger circles.

Residence at Time of Burn	Number of Cases	%
House	3,794	68.7
Apartment	949	17.1
Mobile home	365	6.6
Other	103	1.9
Homeless	56	1.0
Institution	21	0.4
Missing/unknown	243	4.4

Table 4. Residence at Time of Burn

Figure 3. Geographical Location of Residence at Time of Injury



Living Situation at Time of Injury

Figures 4 and 5 depict the living situation of the burn survivor at time of injury, for adults and children, respectively. The majority of adults lived with a spouse, partner, or significant other at the time of injury, whereas the majority of children lived with both parents.





Figure 5. Living With Another Person at Time of Injury: Child



Employment and School Status at Time of Injury

Table 5 describes the employment status of participants over the age of 18 at the time of injury. 1.9% of cases had unknown or missing data for this data point. The majority of adults were employed at the time of injury. Table 6 shows the school status of children ages 5–17 at the time of injury (n = 1,104); the majority of children in this age group were enrolled in school at the time of their burn injury.

Employment Status	Number of Cases	%
Employed	2,210	61.5
Not employed	929	25.9
Retired	336	9.4
Homemaker/caregiver	43	1.2
Volunteer	7	0.2
Missing/unknown	67	1.9

Table 5. Employment at Time of Injury for Participants, 18 Years Old and Older

Table 6. School Status at Time of Injury for Participants 5–17 Years of Age

School Status	Number of Cases	%
In school	916	83.0
Not in school	160	14.5
Missing/unknown	28	2.5

Participants Reporting Pre-Injury Alcohol Use and Drug Use

Table 7 lists pre-injury drug and alcohol use as measured by the CAGE. The amount of missing data for each of these variables varies, but is approximately 14% of the data for each of these data points.

Table 7. Pre-Injury Alcohol and Drug Use

Pre-Injury Alcohol and Drug Use	Number of Cases	%
Alcohol use indicating a potential problem in past 12 months	504	9.1
Drug use indicating a potential problem in past 12 months	407	7.4

Participants Reporting Pre-Existing Physical Disability

Table 8 illustrates prevalence of physical disability prior to burn injury in the sample. Data are missing for 4.7% of the sample for this information.

Table 8. Pre-Injury Disability

Disability	Number of Cases	%
Pre-existing physical disability	415	7.5

Participants Reporting Psychiatric Treatment in the Year Prior to Injury

Table 9 illustrates prevalence of psychiatric treatment prior to burn injury in the sample. Data are missing for 12.3% of the sample for this information.

Table 9. Psychiatric Treatment Pre-Burn

Treatment	Number of Cases	%
Psychiatric treatment in past 12 months	465	8.4

Characteristics of Burn Injury

Total Body Surface Area Burned

Figure 6 shows the distribution of cases in the BMS database by burn size. For patients who had a recorded burn size, 52% were less than 20% TBSA. Patients with a total burn size of 60% TBSA or more accounted for only 7.7% of cases.

Table 10 shows the proportion of participants in each category of total burn size. Very few (<0.5%) participants had burn size that was unknown or not recorded.



Figure 6. Burn Size Categories (% TBSA Burned)

Table 10. Percentage of Total Body Surface Area Burned (TBSA)

TBSA	Number of Cases	%
0–9.9	1,585	28.9
10–19.9	1,265	23.1
20–29.9	857	15.6
30–39.9	580	10.6
40–49.9	469	8.6
50–59.9	307	5.6
60–69.9	201	3.7
70–79.9	126	2.3
80–89.9	67	1.2
≥90	30	0.6
Data missing or 0%	32	0.6
Total	5,519	

Page | 12

Burn Location on the Body

Table 11 describes the bodily location of the burn injury for participants in the BMS database.

Location	Yes	%	Missing/Unknown	%
Head/neck burn	3,071	55.7	69	1.3
Trunk burn	3,482	63.1	59	1.1
Perineum burn*	785	14.2	540	9.8
Arm burn (right, left, or bilateral)	3,889	70.4	56	1.0
Hand burn (right, left, or bilateral)	3,602	65.3	72	1.3
Leg burn (right, left, or bilateral)	3,246	58.8	59	1.1
Foot burn (right, left, or bilateral)	1,710	31.0	86	1.6

Table 11. Burn Injury Location

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

Total Body Surface Area Grafted

The proportion of records with no value for graft size was 10.5%. These included those participants whose graft size was unknown or not recorded. For patients who had a recorded graft size, 72% were less than 20% TBSA. Patients with a total graft size of 50% TBSA or more accounted for only 8% of cases.

Table 12 shows the number and percentage of patients in each category of total graft size.

Percent	Number of Cases	%
0–9.9	2,761	55.9
10–19.9	798	16.2
20–29.9	461	9.3
30–39.9	286	5.8
40–49.9	238	4.8
50–59.9	169	3.4
60–69.9	93	1.9
70–79.9	78	1.6
80–89.9	43	0.9
≥90	14	0.3
Missing/unknown	578	
Total	5,519	

Table 12. Percentage of Total Body Surface Area Grafted

Graft Location

Table 13 describes the burn graft location of participants in the BMS database.

Location	Yes	%	Missing/Unknown	%
Head/neck graft	1,043	18.9	159	2.9
Trunk graft	2,087	37.8	146	2.7
Perineum graft*	341	6.2	747	13.5
Arm graft (right, left, or bilateral)	2,777	50.3	145	2.6
Hand graft (right, left, or bilateral)	2,302	41.7	161	2.9
Leg graft (right, left, or bilateral)	2,386	43.2	139	2.5
Foot graft (right, left, or bilateral)	1,184	21.5	173	3.1

Table 13. Burn Graft Location

*The variable assessing perineum burn was added to data collection later than the other variables on this table.

Cause of Injury

Figure 7 shows the distribution of causes of injury in the BMS database. The proportion of records with a missing value for cause of injury was 1.4%. These included those participants whose cause of injury was unknown or not recorded. For all other participants, 59% of injuries were caused by fire/flame. The other burn category includes abrasions, hydrofluoric acid, frostbite, skin disease, and other causes. The Burn Model System inclusion criteria have changed since the beginning of the program; frostbite and skin disease are no longer eligible causes of injury. Table 14 describes the number of participants and percentage in each injury category.

Figure 8 shows the breakdown of etiology by age category. As seen in this figure, different types of burn are more prevalent for certain age groups.

Figure 7. Cause of Injury



Table 14. Cause of Injury

Cause of Injury	Number of Cases	%
Fire/flame	3,247	58.8
Scald	871	15.8
Grease	397	7.2
Electricity	333	6.0
Contact with hot object	224	4.1
Flash burn	161	2.9
Other	85	1.7
Chemical	86	1.6
Tar	56	1.0
Missing/unknown	58	1.1

Figure 8. Cause of Burn by Age Group



Circumstances and Place of Injury

Table 15 and Figure 9 describe the circumstances of injury in the BMS database. Of participants, 1.9% had an unknown circumstance of injury; the figure is based on participants whose circumstances of injury were known. The vast majority of burn injuries in the database were considered nonintentional, with 16.3% of these related to employment; 6.2% of burns were indicated as intentional.

Table 16 describes the place of injury (closed/indoors versus open/outdoors) in the Burn Model System. The majority of injuries occurred indoors. Figure 10 describes geographical location of injury by total body surface area burned category (based on nonmissing data).

Circumstances of Injury	Number of Cases	%
Nonintentional non-work related	2,875	52.1
Nonintentional employment related	899	16.3
Nonintentional unspecified	660	12.0
Nonintentional recreation	612	11.1
Suspected assault: domestic	127	2.3
Suspected self-inflicted/suicide	122	2.2
Suspected assault: nondomestic	74	1.3
Suspected arson	21	0.4
Not applicable: skin disease*	23	0.4
Missing/unknown	106	1.9

Table 15. Circumstances of Injury

*No longer eligible admission criteria for entry into Burn Model System program.

Figure 9. Circumstances of Injury



Table 16. Place of Injury

Place of Injury	Number of Cases	%
Closed/indoors	3,210	58.2
Open/outdoors	2,138	38.7
Missing/unknown	150	2.7
Not applicable: Skin disease	21	0.4



Figure 10. Location of Injury by Burn Size Category

Inhalation and Other Injuries

Table 17 describes the incidence of inhalation injuries and other injuries in the sample. Table 18 describes these injuries for males and females. This table is based on data that is nonmissing for the injuries and for gender.

Table 17. Inhalation and Other Injuries, and Range of Motion Deficits

Type of Injury	Number of Cases	%
Inhalation injury	825	15.1
Other injury	643	11.8
Range of motion deficit	2,526	45.8

Table 18. Inhalation and Other Injuries by Gender

Gender	%	%
Males	14.3	12.2
Females	16.9	10.8

Treatment Before Discharge

Length of Acute Care Hospital Stay

Figure 11 shows the average length of acute care hospital stay per year. Only 17 records (0.3%) were missing data on the length of hospital stay; the figure is based on participants whose length of stay was known. Length of stay has varied across years, with no downward or upward trend. Average length of stay from 1993–2014 was 29 days. Table 19 shows average length of hospital stay by TBSA burn category. Data about days of hospital stay were missing for 0.3% of participants.

TBSA Burn Category	Average Length of Hospital Stay (Days)
0–9.9	16
10–19.9	20
20–29.9	28
30–39.9	35
40–49.9	42
50–59.9	44
60–69.9	56
70–79.9	69
80–89.9	80
≥90	157

Table 19. Average Length of Hospital Stay by TBSA Burn Category

Figure 11. Length of Acute Care Hospital Stay by Year





Published by Burn Model System National Data and Statistical Center + University of Washington, Seattle, WA + burndata@wu.edu

Ventilator Days

Figure 12 describes the days on a ventilator for different age categories. This figure does not include cases for which these data were missing, which was 4.9% of the sample. Mean number of days on the ventilator was 4 days for the entire sample; the mean number of days for only those who had one or more days on the ventilator was 14 days.





Inpatient Rehabilitation Days

Table 20 describes number of rehabilitation days for the study population. The majority of participants did not go to inpatient rehabilitation upon discharge.

Table 20.	Number	of In	patient	Rehabi	litation	Davs
10010 20.		v	patient			

Number of Inpatient Rehabilitation Days*	Number of Cases	%
Did not go to rehab (0 inpatient rehab days)	3,108	71.1
1–10 days of rehab	137	3.1
11–20 days of rehab	172	3.9
20+ days of rehab	207	4.7
Missing/unknown	747	17.1

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

Hospital Discharge Data

Hospital Disposition

Table 21 describes the disposition upon hospital discharge in the sample, and Figure 13 describes the percentage of each type of disposition for the sample. This figure is based on data that are nonmissing for disposition.



Figure 13. Hospital Discharge

Table 21. Disposition

Disposition	Number of Cases	%
Discharged, patient home	3,640	66.0
Discharged, other home	765	13.9
Other	446	8.1
Discharged, extended home facility	409	7.4
Discharged, other rehab facility (not BMS Center)	82	1.5
Discharged, shelter	27	0.5
Discharged, institution	24	0.4
AMA/unable to complete treatment	14	0.3
Discharged, alcohol/drug treatment center	4	0.1
Discharged, street	5	0.1
Died, burn related	2	0.04
Died, non-burn related	2	0.04
Missing/unknown	99	1.8

Page | 21

Primary Sponsor of Care at Discharge

Table 22 describes the primary sponsor of hospital care at the time of discharge. For this data point, 12.2% of cases had unknown or missing data. Figure 14 describes the percentage of Medicare, Medicaid, private insurance, and no insurance for the group. This figure is based on cases that are nonmissing or unknown for disposition. Types of insurance varied in the sample.

Primary Sponsor of Care at Discharge	Number of Cases	%
Philanthropy; private support	917	16.6
Private insurance	796	14.4
Medicaid	697	12.6
Worker's compensation/L&I	588	10.7
Other	526	9.5
HMO/PPO/prepaid/managed care	454	8.2
Medicare	402	7.3
Self-pay	316	5.7
Indigent; public support	111	2.0
Champus	27	0.5
VA	20	0.4
Missing/Unknown	665	12.1

Table 22. Primary Sponsor of Care at Discharge



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

Treatment After Discharge

Burn-Related Surgeries and Therapy Use

Table 23 describes the postdischarge surgery of patients in the BMS database. Table 24 describes the use of PT/OT and psychological or peer support therapy at each follow-up time-point. These variables have only been collected since 2009; therefore this data applies to only those participants burned in 2009 or later (n = 1,013). Percentages reflect data that is nonmissing. Figure 15 displays the proportion of types of surgery across all time-points combined.

Table 23. Surgeries Since Last Interview

	6 Mon	ths	12 Mor	nths	24 Months	
Surgeries Since Last Interview*	Number of Cases	%	Number of Cases		Number of Cases	%
Participants with burn-related surgeries since last follow-up	168	15.4	206	20.3	221	24.3
Surgery for open wounds**	58		47		37	
Surgery for joint contractures**	97		119		123	
Surgery for scar management**	95		120		150	

*Data collection for these variables began in 2009.

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

Table 24. Therapy Use Since Last Interview

	6 Mor	nths	12 Moi	nths	24 Months	
Therapy Use Since Last Interview*	Number of Cases	%	Number of Cases	%	Number of Cases	%
OT/PT	602	55.3	423	41.5	265	29.0
Psychological or peer support therapy	243	22.7	194	19.3	168	18.6

*Data collection for these variables began in 2009.

Figure 15. Proportion of Types of Surgery at All Follow-Up Points



Page 24

Medical Outcomes After Burn Injury

Scar Problems

Table 25 describes the visible scars and other scar characteristics of patients in the BMS database at each follow-up time-point. These variables have only been collected since 2006; therefore this data applies to only those participants burned in 2006 or later (n = 1,571). Percentages reflect all participants, including those missing data for these data points.

	6 Months		12 M	onths	24 Months		
Scar Problems*	N %		N	%	N	%	
Visible scars	898	83.9	844	84.3	776	85.7	
Dry skin	822	76.2	730	72.1	646	70.5	
Tight skin	690	63.8	568	56.1	480	52.3	
Hypersensitivity	681	63.1	567	56.3	463	50.6	
Fragile skin	598	55.4	487	48.1	428	46.8	
Loss of sensation	556	51.6	494	49.1	430	46.9	
Chronic open wounds	225	20.7	161	15.9	100	10.9	

Table 25. Scar Problems

*Data collection for these variables began in 2006.

Pain, Itch, and Sleep Problems

Table 26 describes the mean level of pain, itch, and sleep problems in the BMS database at each follow-up time-point, based on 0–10 numerical rating scales. These variables have only been collected since 2006; therefore, these data apply only to those participants burned in 2006 or later (n = 1,571). Figure 16 shows the trend in mean pain, itch, and sleep problems over time for those who report these issues (in other words, for those participants who report a 1 or higher on the numeric rating scale; n for each time-point is reported on each figure). Pain and sleep remain relatively constant, while itch trends downward over time. Table 27 shows the percentage of participants at each time-point who had no pain, itch, or sleep problems.

Table 2	26. Pain	, Itch,	and	Sleep	Problems
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	6 Mo	onths	12 Mo	onths	24 Months	
Pain, Itch, and Sleep Problems*	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Pain	3.0 (3.0)	1,085	2.5 (3.0)	1,003	2.2 (2.8)	908
Itch	4.6 (3.2)	1,063	3.8 (3.2)	1,003	2.8 (3.0)	909
Sleep problems	3.2 (3.4)	1,073	2.8 (3.4)	1,005	2.5 (3.3)	908

*Data collection for these variables began in 2006.

Percent of Participants With <u>No</u> Pain, Itch, and Sleep Problems	6 Months	12 Months	24 Months
Pain	31.1%	41.0%	47.8%
Itch	13.4%	20.4%	31.9%
Sleep problems	37.3%	43.3%	48.9%

Table 27. Percentage of Participants With No Pain, Itch, and Sleep Problems

Figure 16. Mean Pain, Itch, and Sleep Problems Over Time for Those Participants Reporting a 1 or Higher on the NRS



Functional Outcomes After Burn Injury

Short Form 12 and 10 Mental and Physical Health Scores

Table 28 describes the mean SF12v2[®] Mental Health Component (MCS) and Physical Health Component (PCS) scores for participants ages 14 and older in the BMS database at each follow-up time-point. Table 29 describes the mean SF10[®] Physical Health Summary (PHS) and Psychosocial Health Summary (PSS) for children ages 0–13. The SF12 variables have been collected since 1997; therefore, the adult data apply only to those participants burned in 1997 or later (n = 3,217). Data collection of the SF10 began in 2006; therefore, the pediatric data apply to children under the age of 14 burned in 2006 or later (n = 441). Mean population norms for the SF12 MCS and PCS are 50 (SD 10); Figure 17 shows the BMS population scores across time as compared to the norm population.

Mean SF12* Scores, Participants Ages 14 and Over	Pre- (Admin at Disc	Burn nistered charge)	rn ered Disch rge)		6 Months		12 Months		24 Months	
	Mean	N	Mean	N	Mean	N	Mean	Ν	Mean	N
MCS	52.1	1,947	46.4	1,932	47.5	1,337	47.6	1,232	47.9	1,061
PCS	52.2	1,947	31.2	1,932	43.4	1,337	45.1	1,232	46.7	1,061

Table 28. Mean SF12 Scores, Participants Ages 14 and Over

*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, US Version 2.0)

Table 29. Mean SF10 Scores, Participants Ages 0-13

Mean SF10* Scores, Participants Ages	Pre-Burn (Administered ges at Discharge)		Discha	Discharge		6 Months		12 Months		24 Months	
0–13	Mean	N	Mean	N	Mean	N	Mean	N	Mean	N	
PHS	52.1	286	30.9	258	43.6	213	46.0	214	46.4	229	
PSS	53.8	285	45.5	273	48.8	217	49.7	216	49.0	232	

*SF-10 for Children[™] © 2001 QualityMetric Incorporated. All Rights Reserved. SF-10 for Children[™] is a trademark of QualityMetric Incorporated.





*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, US Version 2.0)

Social Outcomes After Burn Injury

Employment Status and School Status

Table 30 describes the employment status at follow-up of adults over 18 (n = 3,496) in the BMS database. This variable has not been collected during the entire span of the Burn Models System, and therefore data are missing on 35.8% of participants at 6 months, 43.5% at 12 months, and 52.2% at 24 months. Table 29 describes the school status at follow-up of children between the ages of 5 and 18 (n = 1,104) in the BMS database. Like employment status, this variable was not collected during the entire span of the Burn Model System; therefore, percentages of school status and employment status are based on nonmissing data.

	6 Months		12 Months		24 Months	
Employment Status After Burn Injury, Participants 18 Years of Age and Older*	Number of Cases	%	Number of Cases	%	Number of Cases	%
Working	929	41.1	967	48.8	863	53.4
Not working	1,058	46.8	763	38.5	531	32.9
Homemaker/caregiver	24	1.1	28	1.4	22	1.4
Volunteer	8	0.4	4	0.2	5	0.3
Retired	240	10.6	220	11.1	195	12.1
Missing/unknown	1,175		1,456		1,818	

Table 30. Employment Status After Burn Injury, Participants 18 Years of Age and Older

*Data collection for these variables began in 2009.

Table 31. School Status After Burn Injury, Participants 5–17 Years of Age

	6 Months		12 Months		24 Months	
School Status After Burn Injury, Participants, 5–17 Years of Age*	Number of Cases	%	Number of Cases	%	Number of Cases	%
Same program	291	74.4	276	81.7	243	82.4
New program	41	10.5	29	8.6	31	10.5
Did not resume school	44	11.3	25	7.4	18	6.1
Returned in individual program/home school	15	3.8	8	2.4	3	1.0
Missing/unknown	582		614		672	

*Data collection for these variables began in 2009.

Long-Term Follow-Up Project

Long-Term Outcomes After Burn Injury

The Burn Model System carried out a collaborative project during the 2007–2012 funding cycle to examine outcomes on a subset of participants in the BMS National Database at 5 and 10 years postinjury. Because of this project, the BMS decided to continue to collect information on participants every 5 years postinjury beginning in the 2012–2017 funding period. Tables 32–34 describe physical and mental health scores, depression, and itch of this subset of participants measured at 5 and 10 years postinjury.

Physical and Mental Health Scores at 5 and 10 Years After Injury (Measured With the SF12)

	5 Years At	fter Injury	10 Years After Injury		
Mean SF12* Scores**	Mean	N	Mean	N	
MCS	49.1	228	48.8	228	
PCS	47.9	228	48.7	228	

Table 32. Mean SF12 Scores

*SF-12v2[™] Health Survey © 1994, 2002 by QualityMetric Incorporated and Medical Outcomes Trust. All Rights Reserved. SF-12[®] a registered trademark of Medical Outcomes Trust. (SF12v2 Standard, US Version 2.0) **Normal scores for the U.S. population are 50.0 for MCS and PCS.

Depression at 5 and 10 Years After Injury (Measured With the PHQ-9)

	5 Years At	fter Injury	10 Years After Injury			
PHQ-9 Depression Categories*	%	N	%	N		
None	60.5%	138	58.2%	132		
Mild depression	21.1%	48	23.4%	53		
Moderate depression	12.7%	29	11.5%	26		
Moderately severe depression	2.2%	5	4.0%	9		
Severe depression	3.5%	8	3.1%	7		

Table 33. PHQ-9 Depression Categories

*According to the CDC, nearly 8% of persons in a national survey aged \geq 12 years (6% of males and 10% of females) report moderate or more severe depression.

Itch at 5 and 10 Years After Injury

Table 34. Itch at Long-Term Follow-Up

	5 Years A	fter Injury	10 Years After Injury		
Itch at Long-Term Follow-Up	%	N	%	N	
Experienced itching in the past 2 weeks in the area of the burns, skin grafts, or donor sites	45.9%	150	42.3%	138	

Archived Burn Model System Data

The Burn Model System has collected many other measures in addition to those represented in this report since 1993. Figure 18 is a timeline representing what data have been collected, and when.

Figure 18. Burn Model Systems Variable and Measure Administration



Administered at Follow-up only (6, 12, and 24 months post-injury)

- Administered at Discharge only
- Administered at Discharge and Follow-up
- Administered at long term follow-up (5 and 10 years post injury)

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 and invite participation by external researchers while maintaining the integrity of the data use and confidentiality of the participants.

- Complete a Data Request and Use Agreement Form, available at http://burndata.washington.edu/standard-operating-procedures (under the link for Standard Operation Procedure #604, External Collaboration).
- 2. Email the completed form to the BMS National Data and Statistical Center (NDSC) at burndata@uw.edu.
- 3. The NDSC will share the form with the BMS Project Directors for their review
- 4. Principal Investigator (PI) affiliation, scientific purpose, and scientific overlap with existing approved projects.
- BMS project directors will have 10 working days for comments; the NIDRR BMS Program Manager will make a final decision regarding approval of the proposal with feedback from the NDSC and BMS Project Directors.
- 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 who is familiar with the data and the ways they were collected as a collaborator/consultant.

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