

# Burn Model System Codebook

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This codebook provides information on the structure, contents, and layout of the Burn Model System surveys and includes variable names and coding for those variables.



# Introduction

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This document contains the variable names and coding for all forms used during the assessment of BMS longitudinal database participants. These forms were updated in **2022** when the BMS made changes to measures included in data collection. The past codebook for 2018-2022 contains information about the forms and variables used during that time period.

This codebook serves as a resource for data interpretation and analysis. Included in this document are all surveys used for BMS participants, including adult and pediatric participants, as well as proxy reports for participants under the age of 18. The surveys included are the interview versions of the surveys; the BMS also has similar mail forms for self-administration. Questions and variable names (shown in **red**) that correspond to each question appear in the survey as it is administered, including instructions to the interviewer.

**Numbers for response categories correspond to codes shown unless otherwise noted.**

## **These Codebooks include:**

- Patient Status Codebook, used for all participants (page 6)
- Medical Record Abstraction Form I (used for all participants at discharge) (page 10)
- Medical Record Abstraction Form II (used for all participants at follow-up) (page 16)
- Adult codebooks:
  - Form I Adult Codebook (page 18)
  - Form II Adult Codebook (page 31)
- Pediatric codebooks:
  - Form I Self Report 14-17 (page 52)
  - Form II Self Report 13-17 (page 59)
  - Form II Self Report 8-12 (page 74)
  - Form I Proxy 8-17 (page 83)
  - Form II Proxy 8-17 (page 91)
  - Form I Proxy 0-7 (page 105)
  - Form II Proxy 0-7 (page 112)

\*\*\*\*Note that Form I version are administered at baseline (i.e. discharge) while Form II versions are administered at follow-up (i.e. 6 months, 12 months, 24 months, 5 years, 10 years, etc.).

# Burn Model System Data Collection

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Since 1994, the Burn Model System (BMS) has been collecting data on long term outcomes of burn survivors of all ages. The BMS identified important domains to include in the data collection through new measures and existing publicly available measures.

## Collecting & Coding Data

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

## Scoring Data

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

1. PROMIS-29, PROMIS-25, NIH Toolbox and NeuroQOL measures: <http://www.healthmeasures.net/explore-measurement-systems/overview>
2. Satisfaction with Life Scale (SWL): <https://www.sralab.org/rehabilitation-measures/satisfaction-life-scale>
3. Community Integration Questionnaire Social Integration Subscale (CIQ SIC) <https://www.sralab.org/rehabilitation-measures/community-integration-questionnaire>
4. VR-12: [https://www.rand.org/pubs/research\\_reports/RR1844.html](https://www.rand.org/pubs/research_reports/RR1844.html)
5. Post-Traumatic Check-List-Civilian (PCL-C) <https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp#obtain>
6. Post-Traumatic Growth Inventory (PTGI): <https://www.emdrhap.org/content/wp-content/uploads/2014/07/VIII-B-Post-Traumatic-Growth-Inventory.pdf>

# Burn Model System Centers

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## Boston-Harvard Burn Injury Model System (BHBIMS)

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

In addition to contributing to the national database, the BHBIMS conducts a site-specific study. The aim of this project is to conduct a randomized controlled trial (RCT) using the Stanford Chronic Disease Self-Management Program to provide persons living with burn injury the skills to navigate their recovery and long-term outcomes. Newly generated data from the RCT will further enhance research and models of care for burn injury survivors.

**Project Director:**

Jeffrey Schneider, MD

## North Texas Burn Rehabilitation Model System (NTBRMS)

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

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

**Project Director:**

Karen Kowalske, MD

## Southern California Burn Model System (SCBMS)

The SCBMS is centered in the University of Southern California at the Los Angeles County / University of Southern California Medical Center. The SCBMS serves the greater Los Angeles area which is one of the most diverse economic and ethnic populations in the country. The goal of the center is to conduct high quality research studies based off of the direction of people with burn injuries.

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

### **Project Director:**

Haig Yenikomshian, MD

## Northwest Regional Burn Model System (NWRBMS)

The NWRBMS is centered in the University of Washington Medicine/Surgery area at Harborview Medical Center. NWRBMS's primary activities include conducting research studies on high-priority topics for people with a burn injury. These topics include patients' employment, rehabilitation, depression, and post-burn itching. NWRBMS also provides research-based education and training to professionals and consumers.

In addition to contributing to the national database, the NWRBMS is establishing a web-based dissemination platform to provide education on the challenges and processes encountered after a significant burn injury. The target audiences for this collaborative dissemination project include burn survivors, families, employers, medical professionals, case managers, third-party payers, and agencies involved with worker's compensation and vocational rehabilitation. Additionally, the NWRBMS is working with people experiencing homelessness and King County homeless advocates, medical providers, case managers and outreach workers to understand how disabilities impact the lives of people who are experiencing homelessness and to define and implement improved strategies for engagement in longitudinal research and rehabilitation services.

### **Project Director:**

Barclay Stewart

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

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; and (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.

**Project Director:**

Dagmar Amtmann, PhD

## BMS Patient Status Form

**Instructions:** Fill out this form for all patients eligible for BMS participation. Update the patient status form as needed at follow-up with return to work date and/or death date.

Today's date (mm/dd/yyyy): \_\_\_\_\_

NewMSID (concatenation of site and MSID): \_\_\_\_\_ newmsid

MSID: \_\_\_\_\_ msid

<b>Site (BMS center where care was received):</b>	
<input type="checkbox"/> 1. Dallas—UTSW <input type="checkbox"/> 3. Seattle—UW <input type="checkbox"/> 5. Galveston—UTMB <input type="checkbox"/> 6. Boston—Harvard <input type="checkbox"/> 7. Los Angeles—USC	site
<b>Primary admission criteria to Burn Model System:</b>	
<input type="checkbox"/> 1. 10%+ TBSA 65+ yrs. w/ wound closure surgery <input type="checkbox"/> 2. 20%+ TBSA 19-64 yrs. w/ wound closure surgery <input type="checkbox"/> 3. 20%+ TBSA 0-18 yrs. w/ wound closure surgery <input type="checkbox"/> 4. Elec. high volt./lightning w/ wound closure surgery <input type="checkbox"/> 5. Hand, face, feet burn w/ wound closure surgery	<span style="color: red;">criteria</span>  <u>Variable notes:</u> Recell is considered autografting/ wound closure. Surgery needs to occur within 30 days of burn injury.
<b>Was patient alive at discharge?</b>	
<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No (do not collect DOB or Date of Burn)	alive_dc
<b>Consent at discharge for follow-up?</b>	
<input type="checkbox"/> 1. Yes, consented (continue filling out the rest of the PSF) <input type="checkbox"/> 2. No, did not consent/refused (do not collect DOB or Date of Burn) <input type="checkbox"/> 3. No, did not consent/missed (do not collect DOB or Date of Burn) <input type="checkbox"/> 4. Eligible but unable to consent (severe cognitive impairment due to dementia, TBI, etc) (do not collect DOB or Date of Burn) <input type="checkbox"/> 5. Eligible but unable to consent (language barriers) (do not collect DOB or Date of Burn)	<span style="color: red;">consented</span>  <u>Variable Notes:</u> -- Participants can consent up to 30 days post discharge from the model system (acute or rehab inpatient care). --For the potential participant who is deceased before they can consent, the data should be entered as "2-No, did not consent/refused." --Missed is a category for including people who were eligible for participation but were not approached for the study prior to 30 days post discharge. --If a patient expresses interest and is provided a consent form but never signs or returns it, this is considered a refusal (select "2-No, did not consent/refused.") --Select #4 for severe cognitive impairment for any reason, such as dementia, TBI, active psychosis, cerebral palsy, etc. Select #5 for language barriers, including any language other than English or Spanish.

<p><b>Year of birth:</b> <u>      bth_year      </u> (yyyy) (code 9999 for unknown)</p>	<p><b>Date of birth:</b> <u>      bth_date      </u> (yyyy/mm/dd) (code 1900/09/09 for unknown)</p>
<p><b>Year of burn injury:</b> <u>      brn_year      </u> (yyyy) (code 9999 for unknown)</p>	<p><b>Date of burn injury:</b> <u>      brn_date      </u> (yyyy/mm/dd) (code 1900/09/09 for unknown)</p>
<p><b>Sex:</b> <b>sex</b> (collect via medical record rather than self-report)</p> <p><input type="checkbox"/> 1. Male  <input type="checkbox"/> 2. Female  <input type="checkbox"/> 3. Other, transgender  <input type="checkbox"/> 99. Unknown</p>	
<p><b>Ethnicity and race data collection instructions:</b> These items are administered as self-report in Form I. If the participant consents, fill in this information using their self-reported race/ethnicity. <b>If the eligible patient does not consent</b>, fill in this information at the time of non-consent. If it is appropriate to ask based on interactions with the patient, gather the item by self-report by saying, "I'd like to ask you a question if that is okay...and then read the two questions below. If it is not appropriate, gather the information by medical record.</p>	
<p><b>Ethnicity:</b> <b>ethnicity</b> Hispanic, Latino, or Spanish Origin?</p> <p><input type="checkbox"/> 1. Yes, Hispanic, Latino, or Spanish origin  <input type="checkbox"/> 2. No, not of Hispanic, Latino, or Spanish origin  <input type="checkbox"/> 88. Prefer not to answer  <input type="checkbox"/> 99. Unknown</p>	<p><b>Source of race and ethnicity:</b></p> <p><input type="checkbox"/> 1. Medical record  <input type="checkbox"/> 2. Self report <b>src_ethnicity</b></p> <p><i>Variable notes:</i>  Obtaining ethnicity data from people who do not consent was added with new Forms in 2015. Previous variable, with race and ethnicity combined, was "ethncity" (now archived).The BMS moved to these categories in 2015 to correspond more closely to the way the census captures race/ethnicity data.</p> <p>More changes were made in 2022 to correspond to census data collection:  --Wording for ethnicity was changed to add "Latino or Spanish Origin".  --Wording for "Some other race" was changed (previously worded as "Other").  --Text in for more than one race was added.  --White category was changed (previously worded as "Caucasian/white").</p>
<p><b>Race:</b> <b>race</b></p> <p><input type="checkbox"/> 1. African-American or Black  <input type="checkbox"/> 2. Asian  <input type="checkbox"/> 3. White  <input type="checkbox"/> 4. American Indian/Alaskan Native  <input type="checkbox"/> 5. Native Hawaiian or Other Pacific Islander  <input type="checkbox"/> 6. More than one race (please specify): <b>racemto (text field)</b></p> <hr/> <p><input type="checkbox"/> 7. Some other race (please specify): <b>raceotr (text field)</b></p> <hr/> <p><input type="checkbox"/> 88. Prefer not to answer  <input type="checkbox"/> 99. Unknown</p>	
<p><b>The following questions are only for patients who were <u>alive at discharge and consented</u> to participate in the BMS research study.</b></p>	

<p><b>Date of admission to Model System hospital:</b> <b>enc_date</b> _____</p> <p>(yyyy/mm/dd)</p> <p><u>Coding:</u> I900/09/09 = Unknown</p>	<p><b>Date of 2<sup>nd</sup> hospital admission:</b> <b>enc_date_2nd</b> _____</p> <p>(yyyy/mm/dd)</p> <p><u>Coding:</u> I900/07/07 = Not yet determined I900/08/08 = N/A (no 2<sup>nd</sup> admission) I900/09/09 = Unknown</p>
<p><b>Date of discharge from acute burn care:</b> <i>(if applicable, does not include inpatient rehab)</i> <b>disch_date</b> _____ (yyyy/mm/dd)</p> <p><u>Coding:</u> I900/07/07 = Not yet determined I900/09/09 = Unknown</p>	<p><b>Date of 2<sup>nd</sup> discharge:</b> <i>(if applicable, does not include inpt rehab)</i> <b>disch_date_2nd</b> _____ (yyyy/mm/dd)</p> <p><u>Coding:</u> I900/07/07 = Not yet determined I900/08/08 = N/A (no 2<sup>nd</sup> disch) I900/09/09 = Unknown</p>
<p><b>Date consent form signed by participant:</b> <b>cnsnt_date</b> _____ (yyyy/mm/dd)</p> <p><u>Coding:</u> I900/07/07 = Not yet determined I900/08/08 = Not applicable I900/09/09 = Unknown</p>	
<p><b>Update the information below when follow-up information is obtained after acute burn care discharge:</b></p>	
<p><b>First date of return to work/school since injury:</b> <b>retrndat</b> _____ (yyyy/mm/dd)</p> <p><u>Coding:</u> I900/07/07 = Not yet determined I900/08/08 = Not applicable (no return to work or school) I900/09/09 = Unknown</p>	

Newmsid: \_\_\_\_\_

<b>Date of death:</b>  <b>dth_date</b> _____ (yyyy/mm/dd) <u>Coding:</u> 1900/07/07 = Not yet determined 1900/08/08 = Not applicable (Person Alive) 1900/09/09 = Unknown	<b>Primary Cause of Death ICD-9 Code:</b> _____.____.____ <b>deathcause1</b> <u>Coding:</u> 77777 - Expired: Cause Unknown 88888 - Not Applicable (Person Alive) 99999 - Unknown
	<b>Secondary Cause of Death ICD-9 Code:</b> _____.____.____ <b>deathcause2</b> <u>Coding:</u> 77777 - Expired: Cause Unknown 88888 - Not Applicable (Person Alive) 99999 - Unknown
	<b>Cause of Death E-Code (External Code):</b> _____.____.____ <b>deathcausee</b> <u>Coding:</u> 77777 - Expired: Cause Unknown 88888 - Not Applicable (Person Alive) 99999 - Unknown

## BMS Medical Record Data Abstraction Form: Discharge

**Instructions:** Fill out these items by using the information from the participant's medical record. This should be within 7 days (before or after) of when Form I is filled out with or by the participant. If for any reason an item is gathered by self report, indicate that on this form.

Today's date (mm/dd/yyyy): \_\_\_\_\_

<b>Main cause of burn injury (primary etiology) pretiol</b> <input type="checkbox"/> 1. Fire/flare <input type="checkbox"/> 2. Scald <input type="checkbox"/> 3. Contact with hot object <input type="checkbox"/> 4. Grease <input type="checkbox"/> 5. Tar <input type="checkbox"/> 6. Chemical <input type="checkbox"/> 7. Hydrofluoric acid <input type="checkbox"/> 8. Electricity <input type="checkbox"/> 9. Radiation <input type="checkbox"/> 10. UV light <input type="checkbox"/> 11. Other burn <input type="checkbox"/> 15. Flash burn <input type="checkbox"/> 99. Unknown	<b>Source of etiology of injury:</b> <input type="checkbox"/> 1. Medical record <input type="checkbox"/> 2. Self report src_pretiol
<b>Space/place of burn injury: placeinj</b> <input type="checkbox"/> 1. Closed/indoors <input type="checkbox"/> 2. Open/outdoors <input type="checkbox"/> 99. Unknown	<b>Source of space/place of injury: scr_placeinj</b> <input type="checkbox"/> 1. Medical record <input type="checkbox"/> 2. Self report
<b>Location of burn injury: locinj</b> <input type="checkbox"/> 1. Patient's home <input type="checkbox"/> 2. Other private dwelling <input type="checkbox"/> 3. Patient's place of work <input type="checkbox"/> 4. Other building or structure <input type="checkbox"/> 5. Conveyance (auto, plane, etc) <input type="checkbox"/> 6. Other <input type="checkbox"/> 99. Unknown	<b>Source of location of injury: scr_locinj</b> <input type="checkbox"/> 1. Medical record <input type="checkbox"/> 2. Self report
<b>Circumstances of burn injury: circinj</b> <input type="checkbox"/> 1. Non. intentional employment related <input type="checkbox"/> 2. Non. intentional non. work related ( <i>choose this category if employment and/or recreation do not apply</i> ) <input type="checkbox"/> 3. Non. intentional recreation <input type="checkbox"/> 4. Non. intentional non. specified ( <i>choose this category if there is no information on circumstances other than non. intentional</i> ) <input type="checkbox"/> 5. Suspected assault—domestic <input type="checkbox"/> 6. Suspected assault—non. domestic <input type="checkbox"/> 7. Suspected self. inflicted/suicide <input type="checkbox"/> 8. Suspected arson <input type="checkbox"/> 99. Unknown	<b>Source of circumstances of injury: src_circinj</b> <input type="checkbox"/> 1. Medical record <input type="checkbox"/> 2. Self report
<b>Geographic information of residence pre-injury (fill in using geocoding website):</b>	
<b>State Code:</b> statcode	<b>Tract Code:</b> trctcode
<b>County Code:</b> cntycode	<b>Block Code:</b> blckcode
<b>Latitude:</b> latitude	<b>Longitude:</b> longitude

<b>Status of geographic data: geoid_status</b> <input type="checkbox"/> 0. Address not found in recommended web look-up sites (geo-ID codes will be blank) <input type="checkbox"/> 1. All geocode fields known <input type="checkbox"/> 2. State, County, Census Tract ID and Block Group codes known <input type="checkbox"/> 3. State, County and Census Tract ID codes known <input type="checkbox"/> 4. State and County codes known		<input type="checkbox"/> 5. State code known <input type="checkbox"/> 6. Out of country residence <input type="checkbox"/> 7. Participant declined <input type="checkbox"/> 8. Not applicable, participant is experiencing houselessness <input type="checkbox"/> 9. Address Unknown (geo-ID codes will be blank)	
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<b>Disposition disposn</b> <input type="checkbox"/> 1. Died, burn related <input type="checkbox"/> 2. AMA/Unable to complete treatment <input type="checkbox"/> 3. Discharged, patient home <input type="checkbox"/> 4. Discharged, other home <i>(includes hospital owned apartments)</i> <input type="checkbox"/> 6. Discharged, extended care facility <input type="checkbox"/> 8. Discharged, other rehab facility <i>(not model system)</i>		<input type="checkbox"/> 9. Discharged, institution <input type="checkbox"/> 10. Discharged, drug/alcohol treatment center <input type="checkbox"/> 11. Discharged, shelter <input type="checkbox"/> 12. Discharged, street <input type="checkbox"/> 13. Died, non. burn related <input type="checkbox"/> 14. Other <input type="checkbox"/> 99. Unknown		<b>Source of disposition:</b> <input type="checkbox"/> 1. Medical record <input type="checkbox"/> 2. Self report <b>src_disposn</b>  <i>Variable Note:</i> Text field, "othrehabnote", added to REDCap in March 2018, including information from Boston IRF project. This text field captures more information about category 8, other rehab facility.
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<b>Primary sponsor of care at hospital discharge, or who is paying for the majority of burn care costs (choose only one)? pay_dc</b> <input type="checkbox"/> 1. Medicare <input type="checkbox"/> 2. Medicaid (DSHS) <input type="checkbox"/> 3. Private insurance/HMO/PPO/Pre-Paid/Managed (Collapsed together in 2018) <input type="checkbox"/> 4. Workers' compensation (L&I) <input type="checkbox"/> 6. Champus/Tri. Care (Tri-Care added in 2018)				<input type="checkbox"/> 7. Self. pay or indigent (public support) (Collapsed together in 2018) <input type="checkbox"/> 9. VA <i>Variable Notes:</i> When changes were made in 2018, existing data was pulled and archived so categories that were collapsed could be expanded with historical data, if necessary. <input type="checkbox"/> 10. Other <input type="checkbox"/> 11. Philanthropy (private support or private foundation or Shriners) (Note about Shriners added in 2018) <input type="checkbox"/> 99. Unknown			
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<b>Total number of days on inpatient rehab unit: rhb_days</b>  _____ (code 999 for unknown) (Separate from ICU and burn service days) Coded as '0' when participant did not go to inpatient rehab.		<b>Inhalation injury? inhalinj</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown		<b>Other injury (excluding inhalation injury)?</b> <input type="checkbox"/> 1. No othrinjcat <input type="checkbox"/> 2. Traumatic Brain Injury <input type="checkbox"/> 3. Spinal Cord Injury <input type="checkbox"/> 4. Orthopedic Injury <input type="checkbox"/> 5. Multiple Traumas <input type="checkbox"/> 6. Other <input type="checkbox"/> 99. Unknown	
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<b>Parts of the body burned:</b>			
<b>Head/Face/Neck hnbrn</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown  <i>Variable notes:</i> "Face" added to variable in 2015.	<b>Trunk (back, chest, abdomen) trnkbrn</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown	<b>Perineum (buttocks, genitals) peribrn</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown  <i>Variable notes:</i> "(buttocks, genitals)" added to variable in 2015.	<b>Shoulder/upper arm/elbow suebrn</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown  <i>Variable notes:</i> Prior to 2015, the variable was "armbrn" and did not differentiate upper and lower arm.

*Variable notes:*  
 "(back, chest, abdomen)" added to variable in 2015.

Parts of the body burned, continued:			
<b>Forearm (includes wrist) farmbrn</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown <i>Variable notes:</i> Prior to 2015, the variable was "armbrn" and did not differentiate upper and lower arm.	<b>Hand handbrn</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown	<b>Leg legbrn</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown	<b>Foot footbrn</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown
Parts of the body grafted:			
<b>Head/Face/Neck hngrft</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown <i>Variable notes:</i> "Face" added to variable in 2015.	<b>Trunk (back, chest, abdomen) trnkgrft</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown <i>Variable notes:</i> "(back, chest, abdomen)" added to variable in 2015.	<b>Perineum (buttocks, genitals) perigrft</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown <i>Variable notes:</i> "(buttocks, genitals)" added to variable in 2015.	<b>Shoulder/upper arm/elbow suegrft</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown <i>Variable notes:</i> Prior to 2015, the variable was "armgrft" and did not differentiate between upper and lower arm.
<b>Forearm (includes wrist) farmgrft</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown <i>Variable notes:</i> Prior to 2015, the variable was "armgrft" and did not differentiate between upper and lower arm.	<b>Hand handgrft</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown	<b>Leg leggrft</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown	<b>Foot footgrft</b> <input type="checkbox"/> 1. Right <input type="checkbox"/> 2. Left <input type="checkbox"/> 3. Bilateral <input type="checkbox"/> 4. None <input type="checkbox"/> 99. Unknown
<b>Total body surface area burned (%): tbsabr</b>     _____(xx.x) (code 999 for unknown)	<b>Days on ventilator: daysvent</b>     _____ (code 999 for unknown)	<b>Number of trips to the operating room since injury (other than dressing changes), burn or non-burn related: numtrpor</b>     <i>Variable notes:</i> Coded as '0' when participant has no surgeries _____ (code 999 for unknown)	<b>Date of first surgery for wound closure (includes only autografting or amputation or primary closure of burn wound): surg_date</b>     _____ (code 09/09/1900 for unknown)
<b>Tracheostomy? trach</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown	<b>Documented range of motion deficits? romdef</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 3. Not evaluated <input type="checkbox"/> 99. Unknown	<b>Amputation(s) due to burn at discharge? amputbrn</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown	

<b>Upper extremity amputation (choose all that apply) amput1</b>			
<input type="checkbox"/> 1. Yes, above elbow right amput1__1 <input type="checkbox"/> 2. Yes, above elbow left amput1__2 <input type="checkbox"/> 3. Yes, above elbow bilateral amput1__3 <input type="checkbox"/> 4. Yes, below elbow right amput1__4 <input type="checkbox"/> 5. Yes, below elbow left amput1__5 <input type="checkbox"/> 6. Yes, below elbow bilateral amput1__6 <input type="checkbox"/> 7. Yes, digits only right numudgtr (fill in # of digits) amput1__7 (Thumb amputated? <input type="checkbox"/> 1 Yes <input checked="" type="checkbox"/> 2 No thumbr	<input type="checkbox"/> 8. Yes, digits only left numudgtr (fill in # of digits) amput1__8 (Thumb amputated? <input type="checkbox"/> 1 Yes <input checked="" type="checkbox"/> 2 No thumbl <input type="checkbox"/> 9. Yes, digits only bilateral numudgtrb (fill in # of digits) amput1__9 (Thumbs amputated? <input type="checkbox"/> 1 Yes <input checked="" type="checkbox"/> 2 No thumbbb <input type="checkbox"/> 10. No amput1__10 <input type="checkbox"/> 99. Unknown amput1__99		
Variable notes: For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).			
<b>Lower extremity amputation (choose all that apply) amput2</b>			
<input type="checkbox"/> 1. Yes, above knee right amput2__1 <input type="checkbox"/> 2. Yes, above knee left amput2__2 <input type="checkbox"/> 3. Yes, above knee bilateral amput2__3 <input type="checkbox"/> 4. Yes, below knee right amput2__4 <input type="checkbox"/> 5. Yes, below knee left amput2__5 <input type="checkbox"/> 6. Yes, below knee bilateral amput2__6 <input type="checkbox"/> 7. Yes, digits only right numldgtr (fill in # of digits) amput2__&	<input type="checkbox"/> 8. Yes, digits only left numldgtr (fill in # of digits) amput2__8 <input type="checkbox"/> 9. Yes, digits only bilateral numldgtrb (fill in # of digits) amput2__9 <input type="checkbox"/> 10. Transmetatarsal right (partial foot amputation rt) amput2__10 <input type="checkbox"/> 11. Transmetatarsal left (partial foot amputation left) amput2__11 <input type="checkbox"/> 12. Transmetatarsal bilateral (partial foot amputation bilateral) amput2__12 <input type="checkbox"/> 13. No amput2__13 <input type="checkbox"/> 99. Unknown amput2__99		
Variable notes: For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).			
<b>Clostridioides difficile (C. diff) positive?</b> <input type="checkbox"/> 1. Yes cdiff <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown	<b>Fungal/mold positive? fungmold</b> <i>Note: Do not include Candida or Candidiasis.</i> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown	<b>Heterotopic ossification at discharge? hodc</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown	
<b>COVID diagnosis in hospital (ie, tested positive in the hospital) OR COVID diagnosis pre-hospitalization that is on the medical record? coviddiag</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown		<b>Date of COVID diagnosis: coviddat</b> _____ / _____ / _____ (yyyy/mm/dd) (code 1900/09/09 for unknown)	
<b>Height at admission (cm) heightad</b> _____ (code 999 for unknown)	<b>Weight at admission (kg) weightad</b> _____ (code 999 for unknown)	<b>Height at discharge (cm) htcd</b> _____ (code 999 for unk)	<b>Weight at discharge (kg) wtcd</b> _____ (code 999 for unknown)
<b>Exposed bone at discharge? bone_exp</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. Unknown		<b>Location of exposed bone at discharge locbexp</b> <input type="checkbox"/> 1. Head <input type="checkbox"/> 2. Torso <input type="checkbox"/> 3. Upper extremity <input type="checkbox"/> 4. Lower extremity <input type="checkbox"/> 5. Other <input type="checkbox"/> 77. Not applicable <input type="checkbox"/> 99. Unknown	

<p><b>Exposed tendon at discharge?</b> <span style="color: red;">tendon_exp</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. Unknown</p>	<p><b>Location of exposed tendon at discharge</b> <span style="color: red;">loctexp</span></p> <p><input type="checkbox"/> 1. Head</p> <p><input type="checkbox"/> 2. Torso</p> <p><input type="checkbox"/> 3. Upper extremity</p> <p><input type="checkbox"/> 4. Lower extremity</p> <p><input type="checkbox"/> 5. Other</p> <p><input type="checkbox"/> 77. Not applicable</p> <p><input type="checkbox"/> 99. Unknown</p>
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<b>Co. Morbidities List</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Missing/ 99 Unknown</b>
Has the participant ever been diagnosed with...			
1. Hypertension or high blood pressure? <span style="color: red;">highbp</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Congestive heart failure? <span style="color: red;">conghf</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Myocardial infarction or heart attack? <span style="color: red;">heartatk</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Heart arrhythmias? <span style="color: red;">heartar</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Stroke? <span style="color: red;">stroke</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Emphysema or asthma or COPD? <span style="color: red;">copd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. High blood cholesterol? <span style="color: red;">highchol</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Diabetes, high blood sugar, or sugar in the urine? <span style="color: red;">diabete</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Pneumonia? <span style="color: red;">pneum</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Liver disease (such as hepatitis)? <span style="color: red;">hepat</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Rheumatoid arthritis? <span style="color: red;">rheum</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Osteoarthritis? <span style="color: red;">osteo</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Sleep disorder like sleep apnea? <span style="color: red;">sleepdis</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Cataracts? <span style="color: red;">catar</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Chronic pain? <span style="color: red;">chronpa</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Dementia of some kind, like Alzheimer's? <span style="color: red;">alz</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Parkinson's disease? <span style="color: red;">parkd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Alcoholism? <span style="color: red;">etohadd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Drug addiction? <span style="color: red;">drugadd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Depression? <span style="color: red;">depress</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Anxiety? <span style="color: red;">anx</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Panic attacks? <span style="color: red;">panic</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Bipolar disorder or manic. depression? <span style="color: red;">bipol</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Attention deficit disorder (ADD/attention deficit hyperactivity disorder (ADHD)? <span style="color: red;">adhd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Obsessive. compulsive disorder? <span style="color: red;">ocd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. PTSD (post. traumatic stress disorder)? <span style="color: red;">ptsd</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Spinal cord injury? <span style="color: red;">sci</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Traumatic brain injury? <span style="color: red;">tbi</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Pain Medication Data Collection Table</b> <i>(only pain medication prescribed at discharge OR within 30 days of discharge needs to be collected)</i> <i>Variable notes: 0=not checked and 1=checked (collected as choose all that apply).</i>	
<input type="checkbox"/> 0. No pain medication pmed_dis__0 <input type="checkbox"/> 1. Methadone pmed_dis__1 <input type="checkbox"/> 2. Codeine pmed_dis__2 <input type="checkbox"/> 3. Hydrocodon (Norco, Vicoden) pmed_dis__3 <input type="checkbox"/> 4. Oxycodone (Percodet, OxyContin) pmed_dis__4 <input type="checkbox"/> 5. Hydromorphone (Dilaudid) pmed_dis__5	<input type="checkbox"/> 6. Fentanyl (Duragesic) pmed_dis__6 <input type="checkbox"/> 7. Morphine pmed_dis__7 <input type="checkbox"/> 8. Acetaminophen with codeine (Tylenol #3) pmed_dis__8 <input type="checkbox"/> 9. Gabapentin (Neurontin) pmed_dis__9 <input type="checkbox"/> 10. Amitriptyline pmed_dis__10 <input type="checkbox"/> 99. Unknown pmed_dis__99
<b>Name of Pain Medication (prescribed at discharge), if other than above</b>	
1. meddis1 (text field)	
2. meddis2 (text field)	
3. meddis3 (text field)	
4. meddis4 (text field)	
5. meddis5 (text field)	
6. meddis6 (text field)	
7. meddis7 (text field)	
8. meddis8 (text field)	
9. meddis9 (text field)	
10. meddis10 (text field)	
11. meddis11 (text field)	
12. meddis12 (text field)	

## BMS Medical Record Data Abstraction Form: Follow-up

**Instructions:** Fill out these items by using the information from the participant’s medical record. This data should only be collected if it is within the data collection window of the participant’s follow-up. Otherwise, please indicate that the data is missing/unknown, and enter accordingly into the database.

Medical Record Abstraction Form II added in 2018. This form is not given to participants but collected using the medical record during the follow-up window.

mrafu\_date

Date Medical Record Abstraction Form Collected: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

<p><b>Follow-up period:</b> <span style="color: red;">follow_up</span></p> <p><input type="checkbox"/> 1. 6-month follow-up</p> <p><input type="checkbox"/> 2. 12-month follow-up</p> <p><input type="checkbox"/> 3. 24-month follow-up</p> <p><input type="checkbox"/> 4. 5 year follow-up</p>	<p><input type="checkbox"/> 5. 10 year follow-up</p> <p><input type="checkbox"/> 6. 15 year follow-up</p> <p><input type="checkbox"/> 7. 20 year follow-up</p> <p><input type="checkbox"/> 8. 25 year follow-up</p>
---	---

**Burn Surgeries**  
*Please note:* When the medical record is reviewed for number of surgeries, those surgeries that occurred for **ONLY** a dressing or cast change should **NOT** be counted.

Since the last follow-up, has the participant had any burn related surgeries (such as surgeries for open wounds or scar management)? surgery\_fu\_mra

1. Yes Variable Notes:  
Burn surgeries items moved to MRA form only in 2018. When items were moved to MRA, data from "surgery\_fu" and "surgery\_fuprx" not imported into this new variable, to distinguish data collected from medical record versus self-report (these items were archived).

2. No

99. Unknown

<p><b>How many surgeries did the participant have?</b> <span style="color: red;">numsurg</span> <span style="color: blue;">Variable notes:</span> added in 2015.</p> <p>_____</p> <p><u>Coding:</u>                  77 = N/A—no surgery                  99 = Unknown number of surgeries</p> <p><span style="color: blue;">Surgtype_1 Variable notes:</span>                  There are three other variables in the database, surgtype_2, surgtype_3, and surgtype_4 with the same coding in case more than one or two surgeries were selected. When data was converted in 2018, observations with a "no" for surgery_fu were coded as 77 in surgtype.</p>	<p><b>Which burn related surgeries has the participant had since the last follow-up?</b> <span style="color: red;">surgtype_1</span>                  (Choose all that apply)</p> <p><input type="checkbox"/> 1. Surgery for open wounds</p> <p><input type="checkbox"/> 2. Surgery for joint contractures</p> <p><input type="checkbox"/> 3. Surgery for scar management (laser)</p> <p><input type="checkbox"/> 4. Amputation</p> <p><input type="checkbox"/> 5. Other (if so, what? <span style="color: red;">otrsurg</span> _____)</p> <p><input type="checkbox"/> 77. Not applicable (no surgery)</p> <p><input type="checkbox"/> 99. Unknown</p>
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**Amputations**  
*Instructions:* if the participant hasn’t had surgery for amputation since the last follow-up, fill in “1-No” for these two items amputfu1

**Upper extremity amputation due to burn injury since last follow-up? (Choose all that apply)**

<p><input type="checkbox"/> 1. No upper extremity amputation <span style="color: red;">amputfu1</span> ___1</p> <p><input type="checkbox"/> 2. Yes, above elbow right <span style="color: red;">amputfu1</span> ___2</p> <p><input type="checkbox"/> 3. Yes, above elbow left <span style="color: red;">amputfu1</span> ___3</p> <p><input type="checkbox"/> 4. Yes, above elbow bilateral <span style="color: red;">amputfu1</span> ___4</p> <p><input type="checkbox"/> 5. Yes, below elbow right <span style="color: red;">amputfu1</span> ___5</p> <p><input type="checkbox"/> 6. Yes, below elbow left <span style="color: red;">amputfu1</span> ___6</p> <p><input type="checkbox"/> 7. Yes, below elbow bilateral <span style="color: red;">amputfu1</span> ___7</p>	<p><input type="checkbox"/> 8. Yes, digits only right <span style="color: red;">numudgtrfu</span> _____ (fill in # of <span style="color: red;">amputfu1</span> ___8 digits) (Thumb amputated? <input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 No) <span style="color: red;">thumbbrfu</span></p> <p><input type="checkbox"/> 9. Yes, digits only left <span style="color: red;">numudgtlftfu</span> _____ (fill in # of digits) <span style="color: red;">amputfu1</span> ___9 (Thumb amputated? <input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 No) <span style="color: red;">thumbblfu</span></p> <p><input type="checkbox"/> 10. Yes, digits only bilateral <span style="color: red;">numudgtbfu</span> _____ (fill in # of <span style="color: red;">amputfu1</span> ___10 digits) (Thumbs amputated? <input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 No) <span style="color: red;">thumbbbfu</span></p> <p><input type="checkbox"/> 99. Unknown <span style="color: red;">amputfu1</span> ___99</p>
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Variable notes:  
 For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).

Lower extremity amputation due to burn injury since last follow-up? (choose all that apply) amputfu2	
<input type="checkbox"/> 1. No amputfu2__1	<input type="checkbox"/> 9. Yes, digits only left numldgtfu (fill in # of digits) amputfu2__9
<input type="checkbox"/> 2. Yes, above knee right amputfu2__2	<input type="checkbox"/> 10. Yes, digits only bilateral numldgtbfu (fill in # of digits) amputfu2__10
<input type="checkbox"/> 3. Yes, above knee left amputfu2__3	<input type="checkbox"/> 11. Transmetatarsal right (partial foot amputation rt) amputfu2__11
<input type="checkbox"/> 4. Yes, above knee bilateral amputfu2__4	<input type="checkbox"/> 12. Transmetatarsal left (partial foot amputation left) amputfu2__12
<input type="checkbox"/> 5. Yes, below knee right amputfu2__5	<input type="checkbox"/> 13. Transmetatarsal bilateral (partial foot amputation bilateral) amputfu2__13
<input type="checkbox"/> 6. Yes, below knee left amputfu2__6	<input type="checkbox"/> 99. Unknown amputfu2__99
<input type="checkbox"/> 7. Yes, below knee bilateral amputfu2__7	
<input type="checkbox"/> 8. Yes, digits only right numldgtrfu (fill in # of digits) Variable notes: For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).	
Geographic information of residence at follow-up (fill in using geocoding website):	
<b>State ID:</b> statcodefup	<b>Tract code:</b> trctcodefup
<b>County ID:</b> cntycodefup	<b>Block code:</b> blkcodefup
<b>Latitude:</b> latitudefup	<b>Longitude:</b> longitudefup
<b>Status of geographic data:</b> geoid_statusfup	<i>Variable notes:</i> GeoID variables added in 2022.
<input type="checkbox"/> 0. Address not found in recommended web look-up sites (geo-ID codes will be blank)	<input type="checkbox"/> 5. State code known
<input type="checkbox"/> 1. All geocode fields known	<input type="checkbox"/> 6. Out of country residence
<input type="checkbox"/> 2. State, County, Census Tract ID and Block Group codes known	<input type="checkbox"/> 7. Participant declined
<input type="checkbox"/> 3. State, County and Census Tract ID codes known	<input type="checkbox"/> 8. Not applicable, participant is experiencing houselessness
<input type="checkbox"/> 4. State and County codes known	<input type="checkbox"/> 9. Address Unknown (geo-ID codes will be blank)

Pain Medication Data Collection (only pain medication prescribed within the data collection window needs to be collected)	
<input type="checkbox"/> 0. No pain medication pmed_fup__0	<input type="checkbox"/> 6. Fentanyl (Duragesic) pmed_fup__6
<input type="checkbox"/> 1. Methadone pmed_fup__1	<input type="checkbox"/> 7. Morphine pmed_fup__7
<input type="checkbox"/> 2. Codeine pmed_fup__2	<input type="checkbox"/> 8. Acetaminophen with codeine (Tylenol #3) pmed_fup__8
<input type="checkbox"/> 3. Hydrocodone (Norco, Vicoden) pmed_fup__3	<input type="checkbox"/> 9. Gabapentin (Neurontin) pmed_fup__9
<input type="checkbox"/> 4. Oxycodone (Percodet, OxyContin) pmed_fup__4	<input type="checkbox"/> 10. Amitriptyline pmed_fup__10
<input type="checkbox"/> 5. Hydromorphone (Dilaudid) pmed_fup__5	<input type="checkbox"/> 99. Unknown pmed_fup__99
Name of Pain Medication (prescribed in data collection window), if other than above	
1. med1 (text field)	
2. med2 (text field)	
3. med3 (text field)	
4. med4 (text field)	
5. med5 (text field)	
6. med6 (text field)	
7. med7 (text field)	
8. med8 (text field)	
9. med9 (text field)	
10. med10 (text field)	
11. med11 (text field)	
12. med12 (text field)	

## **BMS Adult Interview Form I: Research Staff Instructions**

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

<b>Form I Administration:</b>		
<p><b>What is the method of administration of this form?</b> <i>admin</i></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>	<p><b>What is the language of administration of this form?</b> <i>language</i></p> <p><input type="checkbox"/> 1. English</p> <p><input type="checkbox"/> 2. Spanish</p>	<p><b>Checklist of forms:</b> <i>status</i></p> <p><b>Mark when each is complete</b></p> <p><input type="checkbox"/> 1. Patient Status Form</p> <p><input type="checkbox"/> 2. Medical Record Abstraction Form</p> <p><input type="checkbox"/> 3. Form I</p>

**Introduction script** (Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

"Thank you for agreeing to participate in this study. The aim of the study is to learn about how people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I'll be asking questions about your burn injury, your health, and other questions about you and people around you. Some questions ask about what things were like before your burn injury, other questions are about your health now. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip." Please let me know at any time if you have any questions."

## Burn Model System Hospital Discharge Survey

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ disintdate

“We’re going to go ahead and get started.”

<b>Section I</b>	
<b>“Please answer each question as it relates to your <u>current</u> health Do you currently have:”</b>	
1. Hearing loss? <span style="color: red;">hlossdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
2. Change in voice? <span style="color: red;">voicedis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
3. Vision problems not corrected by glasses or contact lenses? <span style="color: red;">visiondis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
4. Eyelid problems? <span style="color: red;">eyeliddis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
5. Excessive tearing of the eyes? <span style="color: red;">teardis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
6. Difficulty with memory? <span style="color: red;">memorydis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
7. Difficulty with thought processing? <span style="color: red;">thoughtdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
8. Numbness, pins and needles or burning sensations in your burn scar? <span style="color: red;">numbscdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
9. Numbness, pins and needles or burning sensations in your hands? <span style="color: red;">numbhdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
10. Numbness, pins and needles or burning sensations in your feet? <span style="color: red;">numfdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
11. Trouble with your balance? <span style="color: red;">tbalandis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
12. Varicose veins? <span style="color: red;">varveindis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
13. Swollen feet or legs? <span style="color: red;">swflegdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
14. Swollen hands or arms? <span style="color: red;">swharmdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
15. Skin cancer? <span style="color: red;">skincandis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
16. Joint pain? <span style="color: red;">jpaindis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
17. Have you ever been pregnant or fathered a child? <span style="color: red;">pregfathdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
18. Blood clots in legs or lungs? <span style="color: red;">bcleglungdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
19. Cold intolerance? <span style="color: red;">cintoldis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
20. Excessive sweating? <span style="color: red;">exsweatdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
21. Difficulty in hot environments? <span style="color: red;">difhotdis</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused

## Pre-Injury History Section

“The next section of questions is about your life and your situation before the injury. Your answers will help us understand problems related to the injury. You’ll also be asked similar questions about after your burn injury later in the interview.”

### Section 2

“Here are 4 statements with which you may agree or disagree. Using a scale where 1 represents you strongly disagree and 7 represents that you strongly agree, indicate your agreement with each item by the appropriate choice as it was 4 weeks prior to your burn. Please be open and honest in your response.”

	Strongly disagree =1	Disagree =2	Slightly disagree =3	Neither agree nor disagree =4	Slightly agree =5	Agree =6	Strongly agree =7	
1. In the 4 weeks before my burn, in most ways my life was close to ideal: <span style="color: red;">sl1_pre</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
2. In the 4 weeks before my burn, the conditions of my life were excellent: <span style="color: red;">sl2_pre</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
3. In the 4 weeks before my burn, I was satisfied with my life: <span style="color: red;">sl3_pre</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
4. In the 4 weeks before my burn, I had gotten the important things I wanted in life: <span style="color: red;">sl4_pre</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown

**Section 3** Satisfaction with Life Total Score Variables:  
swlscore\_pre: original, 5 item total score      swlscorepre\_combine: combined 4 and 5 item score.  
swlscore\_pre4item: SWL total score with revised 4-item scale

### During the 4 weeks before your burn:

<p>1. Who usually looked after your personal finances, such as banking and paying bills?</p> <p><input type="checkbox"/> 1. Yourself alone    <span style="color: red;">cia2_pre</span></p> <p><input type="checkbox"/> 2. Yourself and someone else</p> <p><input type="checkbox"/> 3. Someone else</p>	<div style="border: 1px solid black; padding: 2px; width: 80px; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: 80px; margin: 2px auto;">99/Unknown</div>
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<b>Approximately how many times during the 4 weeks before the burn did you participate in the following activities outside of your home?</b>	
2. Shopping <b>ci3_pre</b> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. 1-4 times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
3. Leisure activities such as movies, sports, and restaurants. <b>ci4_pre</b> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. 1-4 times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
4. Visiting friends or relatives <b>ci5_pre</b> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. 1-4 times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<b>During the 4 weeks before your burn:</b>	
5. When you participated in leisure activities did you usually do this alone or with others? <input type="checkbox"/> 1. Mostly alone <b>ci6_pre</b> <input type="checkbox"/> 3. Mostly with family members <input type="checkbox"/> 4. Mostly with friends <input type="checkbox"/> 5. With a combination of family and friends <input type="checkbox"/> 77. Not applicable (no leisure activities)	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
6. Did you have a best friend with whom you confided? <b>ci7_pre</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>

CIQ Social Integration Subscale Total Score Variable: ciqsic\_pre

*Interviewer instructions: Write in 88 for refused or 99 for unknown on this page.*

Section 4											
Please respond to each question or statement by marking one box per row											
	Excellent	Very good	Good	Fair	Poor						
In general, would you say your health before your burn was... <b>global01_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
In general, would you say your quality of life before your burn was... <b>global02_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
In general, how would you rate your physical health before your burn?... <b>global03_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
In general, how would you rate your mental health, including your mood and your ability to think, before your burn?... <b>global04_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
In general, how would you rate your satisfaction with your social activities and relationships before your burn?... <b>global05_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
In general, please rate how well you carried out your usual social activities and roles before your burn. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)... <b>global09r_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
	<b>Completely</b>	<b>Mostly</b>	<b>Moderately</b>	<b>A little</b>	<b>Not at all</b>						
To what extent were you able to carry out your everyday physical activities before your burn, such as walking, climbing stairs, carrying groceries, or moving a chair?... <b>global06_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
<b>In the 4 weeks before your burn...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>						
How often were you bothered by emotional problems such as feeling anxious, depressed or irritable?... <b>global10r_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
<b>In the 4 weeks before your burn...</b>	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very Severe</b>						
How would you rate your fatigue on average?... <b>global08r_pre</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
How would you rate your pain on average?... <b>global07r_pre</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
	<b>No pain</b>										<b>Worst pain imaginable</b>

Section 5	
1. In the month before your burn injury did you take <u>prescription</u> medication for pain on a regular basis? <b>pmed_pre</b>	88/Refused
<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	
In the past 12 months...	
2. In the past 12 months, did you take medication for being worried, tense, or anxious?	88/Refused
<input type="checkbox"/> 1. Yes <b>imed_pre</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	
3. In the past 12 months, did you take medication for being sad, empty, or depressed?	88/Refused
<input type="checkbox"/> 1. Yes <b>wmed_pre</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	
4. Did you receive psychological therapy or counseling in the last 12 months? <b>psychtr</b>	88/Refused
<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	

Section 6	
1. Before your burn injury, where were you living? (Choose only one) <b>resdenc</b>	88/Refused
<input type="checkbox"/> 1. Private residence <input type="checkbox"/> 2. Nursing home <input type="checkbox"/> 3. Adult home <input type="checkbox"/> 4. Correctional institution <input type="checkbox"/> 5. Hotel/motel <input type="checkbox"/> 6. Homeless <input type="checkbox"/> 7. Hospital	<b>99/Unknown</b> <i>Variable Notes:</i> Wording of variable changed with move to new forms in 2015 from "Residence at time of burn injury" to "before your burn injury, where were you living?" In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.
2. What was your zip code at the time of your burn injury? _____ <b>zip_pre</b>	
<input type="checkbox"/> 1 Not applicable (not living in U.S.) <input type="checkbox"/> 2 Not applicable (homeless) (code 99999 for unknown) <b>Checkboxes correspond to variable "zippremiss"</b>	
3. Who were you living with before your burn injury? (Choose all that apply)	88/Refused
<input type="checkbox"/> 1. Alone <b>livinga__1</b> <input type="checkbox"/> 2. Spouse/partner/significant other <b>livinga__2</b> <input type="checkbox"/> 3. Friend <b>livinga__3</b> <input type="checkbox"/> 4. Parent or step-parent <b>livinga__4</b> <input type="checkbox"/> 5. Other relative (siblings, grandparents) <b>livinga__5</b> <input type="checkbox"/> 6. Others, not part of family <b>livinga__6</b> <input type="checkbox"/> 7. Guardian <b>livinga__7</b> <input type="checkbox"/> 8. Young children <b>livinga__8</b> <input type="checkbox"/> 9. Adult children <b>livinga__9</b> <input type="checkbox"/> 99. I don't know <b>livinga__99</b>	<b>livinga__98</b> <i>Variable notes:</i> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).

<p>4. What was your marital status at the time of your burn injury? (Choose only one)</p> <p><input type="checkbox"/> 1. Married; living common-law or with a partner <b>martstatpre</b></p> <p><input type="checkbox"/> 2. Separated</p> <p><input type="checkbox"/> 3. Divorced</p> <p><input type="checkbox"/> 4. Widowed</p> <p><input type="checkbox"/> 5. Single (not married)</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p><i>If clarification about this item is needed, say, "We appreciate this information because income is often related to health. For instance, we'd like to know if families with lower reported income have more trouble accessing health care, such as dental care or physical therapy. Having this information helps us advocate for better programs that serve people with burn injuries."</i></p>	
<p>5. Approximately what was your family's total income in the last full year before your burn injury (total income of all family members living with you in your household)? (in U.S. dollars)</p> <p><input type="checkbox"/> 1. Less than \$25,000 <b>hinccatpre</b></p> <p><input type="checkbox"/> 2. \$25,000-\$49,999</p> <p><input type="checkbox"/> 3. \$50,000-\$99,999</p> <p><input type="checkbox"/> 4. \$100,000-\$149,999</p> <p><input type="checkbox"/> 5. \$150,000-\$199,999</p> <p><input type="checkbox"/> 6. \$200,000 or more</p> <p><input type="checkbox"/> 7. Living outside the United States</p> <p><input type="checkbox"/> 77. Not applicable (e.g., living in an institution)</p> <p><input type="checkbox"/> 88. Prefer not to answer</p>	<div style="border: 1px solid black; padding: 2px;">99/Unknown</div> <p><i>Variable notes:</i> Wording on this variable was changed to "family" from "household" in 2022.</p>
<p>6. How many people are in your household? _____ <b>numhspre</b></p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p>7. In the year prior to your burn injury, how many months did you work for pay? <b>mrjobpre</b></p> <p><input type="checkbox"/> 99. I don't know (fill in # of months)</p> <p><input type="checkbox"/> 0. Less than 1 month</p> <p><input type="checkbox"/> 77. Not applicable (did not work in the past year)</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
<p>8. Before your burn (or the last time you worked, if the answer to the above was less than 1 month), what was your primary occupation?</p> <p>Occupation: _____ <b>occpre</b> (not name of company)</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p>Occupation Categories [for staff use only] <b>occpre</b> <i>Variable notes: This is coded by data collectors.</i></p> <p>1 - Executive, Administrative, And Managerial, 2 - Professional Specialty, 3 - Technicians And Related Support , 4 - Sales, 5 - Administrative Support Including Clerical, 6 - Private Household, 7 - Protective Service, 8 - Service, Except Protective And Household, 9 - Farming, Forestry, And Fishing, 10 - Precision Production, Craft, And Repair, 11 - Machine Operators, Assemblers, And Inspectors, 12 - Transportation And Material Moving, 13 - Handlers, Equipment Cleaners, Helpers, And Laborers, 14 - Military Occupations</p>	

Employpre variable notes:

Wording changed in 2015 from "employment status at time of burn" to "what was your employment status at the time of your burn?" Response options changed from one category, "not working", to two categories, "not working (looking for work)" and "not working (not looking for work)". The response category 8, "N/A, 0-4 age group" removed due to shift to separation of pediatric forms. The use of the previous code for 2, "not working", is no longer in use in the new data collection forms. Data that was collected as "not working" in the old versions of the forms is now stored in the variable "employpre" as "66-not working on previous data collection".

NewMSID #:

<p>9. What was your employment status at the time of your burn? (Choose only one) <b>employpre</b></p> <p><input type="checkbox"/> 1. Working </p> <p><input type="checkbox"/> 2. Not working (looking for work)</p> <p><input type="checkbox"/> 3. Not working (<u>not</u> looking for work)</p> <p><input type="checkbox"/> 4. Homemaker/caregiver</p> <p><input type="checkbox"/> 5. Volunteer</p> <p><input type="checkbox"/> 6. Retired</p>	<p>88/Refused</p> <p>99/Unknown</p> <p>(If you were working) Before your burn, about how many <u>hours a week</u> did you work for pay?</p> <p><b>hpaypre</b></p> <p>_____</p> <p>(fill in # of hours)</p>
<p><i>Interviewer Instructions: Skip#10 and move on to #11 if the participant declined to answer the household income question or if the participant is a one-person household (fill in income from household question if the participant is a one-person household).</i></p> <p>10. Approximately what was your individual income in the last full year before your burn injury? (in U.S. dollars) <b>iinccatpre</b></p> <p><input type="checkbox"/> 1. Less than \$25,000</p> <p><input type="checkbox"/> 2. \$25,000-\$40,999</p> <p><input type="checkbox"/> 3. \$41,000-\$55,999</p> <p><input type="checkbox"/> 4. \$56,000-\$70,999</p> <p><input type="checkbox"/> 5. \$71,000-\$85,999</p> <p><input type="checkbox"/> 6. \$86,000-\$100,000</p> <p><input type="checkbox"/> 7. Greater than \$100,000</p> <p><input type="checkbox"/> 8. Living outside the United States</p> <p><input type="checkbox"/> 77. Not applicable (no individual income)</p> <p><input type="checkbox"/> 88. Prefer not to answer</p>	
<p>11. Were you going to school at the time of your burn injury? <b>aschool</b></p> <p><input type="checkbox"/> 1. In school</p> <p><input type="checkbox"/> 2. Not in school </p>	<p>If you were not working or going to school at the time of your burn injury, why not? <b>whynot</b></p> <p><input type="checkbox"/> Not applicable (working or going to school) =77</p> <p><input type="checkbox"/> Medical problems =2</p> <p><input type="checkbox"/> Problems with employer =3</p> <p><input type="checkbox"/> Emotional/social reasons =4</p> <p><input type="checkbox"/> Legal reasons/jail =5</p> <p><input type="checkbox"/> Substance abuse =6</p> <p><input type="checkbox"/> Personal choice =7</p> <p><input type="checkbox"/> Other =8</p> <p><input type="checkbox"/> Retired =9</p> <p><input type="checkbox"/> Homemaker/caregiver =10</p> <p><input type="checkbox"/> Unemployed but actively seeking employment =11</p> <p><input type="checkbox"/> I don't know =99</p>
<p>12. Before your burn injury, did you have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? <b>physprobpre</b></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> <p><i>Variable notes:</i> This variable replaced "physdis" in 2015.</p>	

13. Before your burn injury, were you ever told by a doctor that you had any of the following psychological issues (choose all that apply)? **psychlist** 88/Refused

- 0. None/no psychological issues
- 1. Depression
- 2. Bipolar disorder
- 3. Anxiety
- 4. Post-Traumatic Stress Disorder (PTSD)
- 5. Schizophrenia/psychotic disorder
- 6. Other, please explain: psychlistot (text field)
- 99. I don't know

*Variable notes:*  
There are two other variables in the database, psychlist2 and psychlist3 with the same coding in case more than one or two issues were selected.

<b>Section 7</b>			
<i>Interviewer instructions:</i> This section asks about alcohol use in the past year.			
If the participant did not drink alcohol in the past year, <b>mark this box</b> <input type="checkbox"/> and then skip to Section 8 below. <span style="color: red; font-size: small;">If this box is marked, the rest of the variables are coded as 77=Not applicable</span>			
“In the past year...”			
<b>cageetoh1</b>	1. Have you felt you needed to cut down on your drinking?	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
<b>cageetoh2</b>	2. Have people annoyed you by criticizing your drinking?	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
	3. Have you ever felt guilty about drinking? <b>cageetoh3</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
	4. Have you ever felt you needed a drink first thing in the morning (eye-opener) to steady your nerves or to get rid of a hangover? <b>cageetoh4</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
<b>Section 8</b>			
<i>Interviewer instructions:</i> This section asks about drug use in the past year.			
If the participant did not use drugs in the past year, <b>mark this box</b> <input type="checkbox"/> and then skip to Section 9 on the next page. <span style="color: red; font-size: small;">If this box is marked, the rest of the variables are coded as 77=Not applicable</span>			
“The questions in this section are asking about use of drugs like crack or heroin; or about prescription drugs like pain killers or stimulants that were not prescribed to you; or chemicals you might have inhaled or 'huffed'. We also want to know if sometimes you took more than you should have of any drugs that have been prescribed to you.”			
In the past year...			
<b>cagedrug1</b>	1. Have you felt you needed to cut down on your drug use?	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
<b>cagedrug2</b>	2. Have people annoyed you by criticizing your drug use?	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
	3. Have you ever felt guilty about your drug use? <b>cagedrug3</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown
	4. Have you ever felt you needed to use drugs first thing in the morning (eye-opener) to steady your nerves or to get rid of a hangover? <b>cagedrug4</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	88/Refused 99/Unknown

*Variable notes:*  
For these two variables, the summary variable, "etohabu" and "drugabu", is coded as a yes =1 if the participant answered two or more of these questions with "yes" (CAGE=2, 3, or 4). The summary variables are coded as "No"=2 if the participant answered 1 or no questions with "yes" (CAGE=0 or 1).

### Post-Injury History Section

“All the questions you just answered were about the time before your burn injury. Now I’ll ask some similar questions, but they are about the time since your burn injury. As a reminder, some of these questions can feel repetitive but it’s part of the research process. Thank you for your patience.”

Section 9												
In the past 7 days, or since your burn if you were injured less than 7 days ago...												
How would you rate your pain on average?...												
<div style="border: 1px solid black; padding: 2px; margin-bottom: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>	<span style="color: red;">global07_dis</span> 0 <b>No pain</b>	<input type="checkbox"/>										
										8	9	10 <b>Worst pain imaginable</b>

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

Section 10					
Please respond to each question or statement by marking one box per row					
In the past 7 days, or since your burn if you were injured less than 7 days ago...	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
	<b>Not at all</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Quite a bit</b>	<b>Very much</b>
How difficult was it for you to take in new information because of pain? <span style="color: red;">painin1_dis</span>	<input type="checkbox"/>				
How much did pain interfere with your enjoyment of life? <span style="color: red;">painin3_dis</span>	<input type="checkbox"/>				
How much did pain make it difficult to fall asleep? <span style="color: red;">painin19_dis</span>	<input type="checkbox"/>				
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
How often was pain distressing to you? <span style="color: red;">painin24_dis</span>	<input type="checkbox"/>				
How often was your pain so severe you could think of nothing else? <span style="color: red;">painin29_dis</span>	<input type="checkbox"/>				
How often did pain make you feel anxious? <span style="color: red;">painin37_dis</span>	<input type="checkbox"/>				

PROMIS Pain Interference Total Score Variable: painintscore\_dis

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section 11</b>		
<b>Please respond to each question or statement by marking one box per row</b>		
<b>In the past 7 days, or since your burn if you were burned less than 7 days ago...</b>		
How intense was your itch in general?..... piqseverity05_dis	<input type="checkbox"/> 0=0 No itch <input type="checkbox"/> 1=1 <input type="checkbox"/> 2=2 <input type="checkbox"/> 3=3 <input type="checkbox"/> 4=4 <input type="checkbox"/> 5=5 <input type="checkbox"/> 6=6 <input type="checkbox"/> 7=7 <input type="checkbox"/> 8=8 <input type="checkbox"/> 9=9 <input type="checkbox"/> 10=10 Worst imaginable itch	If no itch in the past 7 days, or since the burn if they were burned less than 7 days ago, skip to Section 12 on page 12.  If the participant did have itch in the past 7 days, or since the burn if they were burned less than 7 days ago, continue on with the rest of Section 11, below.
<div style="border: 1px solid black; display: inline-block; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; display: inline-block; padding: 2px;">99/Unknown</div>		

<b>Please respond to each question or statement by marking one box per row</b>					
<b>In the past 7 days, or since your burn if you were burned less than 7 days ago ...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
because of itch, it was hard to work piqgeneral65_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, it was hard to do even simple tasks piqgeneral56_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I made more mistakes than normal piqgeneral54_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, it was hard to watch television piqgeneral49_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Please respond to each question or statement by marking one box per row</b>					
<b>In the past 7 days, or since your burn if you were burned less than 7 days ago ...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
because of itch, I felt miserable piqmoodsleep40_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I felt sad piqmoodsleep37_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I was restless piqmoodsleep58_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I had difficulty falling asleep piqmoodsleep60_dis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**PROMIS Itch Total Score Variables:**

itchinttscore\_dis: Itch Interference T-score

itchmmtsore\_dis: Itch Mood and Sleep T-score

**Section 12**1. Are you of Hispanic, Latino, or Spanish Origin? **ethnicity**

1. Yes, Hispanic, Latino, or Spanish origin
2. No, not of Hispanic, Latino, or Spanish origin
88. Prefer not to answer

99/Unknown

2. What is your race? **race**

1. African-American or Black
2. Asian
3. White
4. American Indian/Alaskan Native
5. Native Hawaiian or Other Pacific Islander
6. More than one race ((please specify): **racemto (text field)**)
7. Some other race (please specify): **raceotr (text field)** \_\_\_\_\_
88. Prefer not to answer

99/Unknown

**Section 13**

This is the last section of the survey

1. After your hospital discharge, where are/will you be living? (Choose only one) **dislivsit**

1. Private residence
2. Nursing home
3. Adult home
4. Correctional institution
5. Hotel/motel
6. Homeless
7. Hospital
99. I don't know

Variable Notes:

In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). When changes were made in 2018, previously collected data was archived.

88/Refused

2. Who will you be living with after hospital discharge? (Choose all that apply)

1. Alone **livhsdis\_\_1**
2. Spouse/partner/significant other **livhsdis\_\_2**
3. Friend **livhsdis\_\_3**
4. Parent or step-parent **livhsdis\_\_4**
5. Other relative (siblings, grandparents) **livhsdis\_\_5**
6. Others, not part of family **livhsdis\_\_6**
7. Guardian **livhsdis\_\_7**
8. Young children **livhsdis\_\_8**
9. Adult children **livhsdis\_\_9**
99. I don't know **livhsdis\_\_99**

88/Refused

**livhsdis\_\_88**Variable notes:

For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).

3. How many years of education have you completed? **educdis**  
 (If you have not graduated from high school, please indicate the number of years spent in school. If you have at least a high school diploma, please indicate the highest degree earned or worked toward post-high school. In other words, what is the highest level of education you have completed?)

- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 4. 4 years
- 5. 5 years
- 6. 6 years
- 7. 7 years
- 8. 8 years
- 9. 9 years
- 10. 10 years
- 11. 11 or 12 years; no diploma
- 12. High school diploma or equivalent (ie, GED) (GED added to this option in 2022)
- 13. Work towards Associate's degree, vocational degree, or trade school diploma/cert.
- 14. Associate's degree, vocational degree, or trade school diploma/certificate
- 15. Work towards Bachelor's degree
- 16. Bachelor's degree
- 17. Work towards Master's degree
- 18. Master's degree
- 19. Work towards doctorate level degree
- 20. Doctoral level degree
- 66. Other

88/Refused  
 99/Unknown

4. Are you currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)

- 1. I am not receiving disability income **disincedis\_\_1**
- 2. Social Security Disability **disincedis\_\_2**
- 3. Private long term insurance disability income **disincedis\_\_3**
- 4. Supplemental security income (SSI) **disincedis\_\_4**
- 5. Worker's compensation **disincedis\_\_5**
- 6. Other (please specify) **disincedis\_\_6** **disincediso (text field)**
- 99. I don't know **disincedis\_\_99**

88/Refused  
**disincedis\_\_88**  
*Variable notes:*  
 For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).

5. Have you ever served in the military? **mildis**

- 1. No
- 2. Yes

88/Refused  
 99/Unknown

Length of interview: **length** \_\_\_\_\_

"Is there anything else you would like to tell us? **commentsdis1** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

"We'll be contacting you in about 6 months to see how you are doing. Thank you very much for sharing your experiences with us!"

## BMS Adult Interview Form II: Research Staff Instructions

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead. Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

<b>Form II Administration:</b>	
<b>Follow-up period</b> <i>follow_up</i> <input type="checkbox"/> 1. 6-month follow-up <input type="checkbox"/> 5. 10 year follow-up <input type="checkbox"/> 2. 12 month follow-up <input type="checkbox"/> 6. 15 year follow-up <input type="checkbox"/> 3. 24 month follow-up <input type="checkbox"/> 7. 20 year follow-up <input type="checkbox"/> 4. 5 year follow-up <input type="checkbox"/> 8. 25 year follow-up	
<b>What is the method of administration of this form?</b> <input type="checkbox"/> 2. Mail <i>admin_fup</i> <input type="checkbox"/> 5. Medical Record Review	<b>What is the language of administration of this form?</b> <i>language_fup</i> <input type="checkbox"/> 1. English <input type="checkbox"/> 2. Spanish
<b>What is the status of this follow-up assessment?</b> <i>lostfolo</i> <input type="checkbox"/> 1. Some or all assessment done <input type="checkbox"/> 2. Death due to burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 3. Death due to non-burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 4. Unable to locate <input type="checkbox"/> 5. Refused this assessment <input type="checkbox"/> 6. Unable to test/med comp/incapable of responding <input type="checkbox"/> 7. Failed to respond <input type="checkbox"/> 8. Did not consent to future assessment/withdrew <input type="checkbox"/> 11. Incarcerated <input type="checkbox"/> 13. Still in hospital (not discharged yet) <input type="checkbox"/> 14. Unable to travel for assessment <input type="checkbox"/> 15. Death (unknown causes) (update date and cause of death on Patient Status Form)	
<b>If follow-up status is "unable to locate," mark the best reason, below:</b> <i>unabletolocate</i> <input type="checkbox"/> 1. Homeless at previous data collection <input type="checkbox"/> 2. International place of residence <input type="checkbox"/> 3. Participant is child who was/is in CPS custody or foster care and no contact information is available <input type="checkbox"/> 4. No known current contact info <input type="checkbox"/> 5. Other reasons <input type="checkbox"/> 6. Unable to contact due to Shriners Hospital regulations	

## Burn Model System Follow-up Survey

**Introduction Script** (replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

“Hi my name is \_\_\_\_ and I am calling from \_\_\_\_\_ to ask you some questions about how you have been doing (since your injury)... or (since we last spoke with you on (last follow-up date)). Thank you for continuing to participate in our study. The aim of the study is to learn about how people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I’ll be asking questions about your burn injury, your health, and other questions about you and people around you. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.” Please let me know at any time if you have any questions.”

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ fup\_date

“As a reminder, your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.”

“We’re going to go ahead and get started.”

### Section I

1. What is your primary mode of transportation? transport

- 1. Driving my own vehicle
- 2. Riding with someone else
- 3. Public transit
- 4. Not applicable (I don’t use motorized transport)

88/Refused

99/Unknown

Variable notes: The previous variable “drive” was changed in 2018 to include transportation options other than driving a car. This new variable was adopted from Traumatic Brain Injury Model Systems.

2. Since your last research study questionnaire, have you spoken with other burn survivors to get support for problems related to your burn injury? peersup

- 1. Yes
- 2. No
- 99. I don’t know

88/Refused

3. To your knowledge, in the last year have you had COVID-19? **covidstat**

*Or, if this is a 6 month interview, say, Since your last research study questionnaire, have you had COVID-19?*

- 1. Yes **—————>**
- 2. No
- 99. I don't know

88/Refused

Variable notes: COVID items added in 2022.

(If yes), What month and year did you have COVID-19? (if you've had COVID-19 more than once, provide the month and year of your first illness)

Month: **covidmonth**  
Year: **covidyear**

88/Refused  
99/Unknown

What level of care did you receive for COVID-19? **covidcare**

- 1. Did not seek medical care
- 2. Received medical care but was not hospitalized
- 3. Was hospitalized
- 88. Refused
- 99. Unknown

In the hospital... (if applicable) **covidvent**

- 1. I was NOT on a ventilator (breathing machine with tube down your throat)
- 2. I was on a ventilator
- 3. I don't know

88/Refused

4. Since your last research study questionnaire, have you received any of the following services at home or outpatient? (Choose all that apply)

- 1. No services **services\_\_1**
- 2. Occupational therapy **services\_\_2**
- 3. Physical therapy **services\_\_3**
- 4. Speech language pathology **services\_\_4**
- 5. Social work **services\_\_5**
- 6. Psychological services **services\_\_6**
- 7. Vocational services **services\_\_7**
- 99. I don't know **services\_\_99**

*If clarification is needed, say "Examples of occupational therapy include helping with adaptive equipment and work environment after an injury. Examples of physical therapy include range of motion and walking exercises."*

88/Refused

Variable notes:

For each variable, 0 ="no"(not checked) and 1= "yes" (checked)

**services** 88

**Interviewer instructions: If the participant didn't receive any services OR if they didn't receive PT/OT, skip to #9 on page 4**

5. If yes to OT and/or PT, How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? (If you don't know exactly, use your best guess) **numther**

- 1. One
- 2. 2 to 4
- 3. 5 to 10
- 4. More than 10
- 77. Not applicable (no OT/PT received) **—————>** skip to #9 on page 4
- 99. I don't know

88/Refused

Variable notes: Previous variable "numserv" was changed to be multiple choice rather than fill in the blank. Data from "numserv" was categorized and then moved into "numther." "Numserv" was archived.

If yes to OT and/or PT, Since your last research study questionnaire, <u>where</u> did you receive your outpatient occupational or physical burn therapy?	
6. At the burn center? <b>ther_brn_ctr</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 77. Not applicable (no OT/PT received) <input type="checkbox"/> 99. I don't know	88/Refused
7. At any other facility? <b>ther_otr</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 77. Not applicable (no OT/PT received) <input type="checkbox"/> 99. I don't know	88/Refused
8. Using telehealth? (for example, meeting with your therapist using video conferencing) <b>telehlth</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 77. Not applicable (no OT/PT received) <input type="checkbox"/> 99. I don't know	88/Refused
9. Since your last research study questionnaire, have you had any burn related surgeries (such as surgeries for open wounds or scar management)? <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know <b>surgery_fu</b>	(If the participant <u>did</u> have burn related surgeries) Have you had any burn-related surgeries outside of this clinical center? <b>surgout</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know
88/Refused	88/Refused

<b>Section 2</b>				
<b>Please answer each question as it relates to your current health</b>				
<b>Do you currently have:</b> <i>Variable Codes: For all ROS items, 1=Yes, 2=No, 88=Declined to answer/Refused, 99=Missing/unknown</i>				
1. Hearing loss? <b>hloss</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
2. Change in voice? <b>voice</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
3. Vision problems not corrected by glasses or contact lenses? <b>vision</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
4. Eyelid problems? <b>eyelid</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
5. Excessive tearing of the eyes? <b>tear</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
6. Difficulty with memory? <b>memory</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
7. Difficulty with thought processing? <b>thought</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused
8. Numbness, pins and needles or burning sensations in your burn scar? <b>numbsc</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	<input type="checkbox"/> Refused

9. Numbness, pins and needles or burning sensations in your hands? <b>numbh</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
10. Numbness, pins and needles or burning sensations in your feet? <b>numbf</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
11. Trouble with your balance? <b>tbalan</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
12. Varicose veins? <b>varvein</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
13. Swollen feet or legs? <b>swfleg</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
14. Swollen hands or arms? <b>swharm</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
15. Difficulty breathing when doing your regular daily activities? <b>difbrereg</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
16. Skin cancer? <b>skincanc</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
17. Joint pain? <b>jpain</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
18. Have you been pregnant or fathered a child since your last research study questionnaire? <b>preg_fath</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
19. Blood clots in legs or lungs? <b>bclelung</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
20. Cold intolerance? <b>cintol</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
21. Excessive sweating? <b>exsweat</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
22. Difficulty in hot environments? <b>difhot</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
23. Is your skin more sensitive than before your burn? <b>skinsens</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Refused

**Section 3**

1. Are you **currently** taking prescription medication for pain on a regular basis? **pmed\_curr**

1. Yes  
 2. No  
 99. I don't know

88/Refused

2. Are you **currently** taking prescription medication for itch on a regular basis? **imed**

1. Yes  
 2. No  
 99. I don't know

88/Refused

3. In the **past 12 months**, did you take medication for being, worried, tense, or anxious? **wmed**

1. Yes  
 2. No  
 99. I don't know

88/Refused

4. In the past 12 months, did you take medication for being sad, empty, or depressed? **smed**

1. Yes  
 2. No  
 99. I don't know

88/Refused

5. Since your last research study questionnaire, have you received psychological therapy or counseling due to your burn injury? **pyschther**

88/Refused

- 1. Yes
- 2. No
- 99. I don't know

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section 4</b>					
<b>Please respond to each question or statement by marking one box per row</b>					
<b>In the past 7 days...</b>					
How intense was your itch in general?..... <b>piqseverity05</b>	<input type="checkbox"/> 0=0 No itch <b>—————&gt;</b> <input type="checkbox"/> 1=1 <input type="checkbox"/> 2=2 <input type="checkbox"/> 3=3 <input type="checkbox"/> 4=4 <input type="checkbox"/> 5=5 <input type="checkbox"/> 6=6 <input type="checkbox"/> 7=7 <input type="checkbox"/> 8=8 <input type="checkbox"/> 9=9 <input type="checkbox"/> 10=10 Worst imaginable itch	<i>If the participant did not have any itch in the past 7 days, skip to Section 5 on page 7.</i>  <i>If they did have itch in the past 7 days, continue on with the rest of Section 4</i>			
<b>Please respond to each question or statement by marking one box per row</b>					
<b>In the past 7 days...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
because of itch, it was hard to work <b>piqgeneral65</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, it was hard to do even simple tasks <b>piqgeneral56</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I made more mistakes than normal <b>piqgeneral54</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, it was hard to watch television <b>piqgeneral49</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Please respond to each question or statement by marking one box per row					
In the past 7 days...	Never	Rarely	Sometimes	Often	Almost Always
because of itch, I felt miserable <b>piqmoodsleep40</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I felt sad <b>piqmoodsleep37</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I was restless <b>piqmoodsleep58</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
because of itch, I had difficulty falling asleep <b>piqmoodsleep60</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Itch Total Score Variables:*

*itchintscore: PROMIS Itch Interference v1.0 4a t-score & itchmtscore: PROMIS Itch Mood and Sleep v1.0 4a t-score*

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

Section 5					
Please respond to each question or statement by marking one box per row.					
<b>global01</b>	Excellent	Very good	Good	Fair	Poor
In general, would you say your health is:...	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
In general, would you say your quality of life is: <b>global02</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
In general, how would you rate your physical health? <b>global03</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
In general, how would you rate your mental health, including your mood and your ability to think? <b>global04</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
In general, how would you rate your satisfaction with your social activities and relationships? <b>global05</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.) <b>global09r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

	Completely	Mostly	Moderately	A little	Not at all
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? <i>global06</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
<b>In the past 7 days...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable? <i>global10r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
<b>In the past 7 days...</b>	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very Severe</b>
How would you rate your fatigue on average? <i>global08r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

*PROMIS Global v1.2 Total Score Variables: globalmetscore\_pre: Mental health t-score & globalptscore\_pre: Physical health t-score*

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section 6</b>					
<b>Please respond to each question or statement by marking one box per row.</b>					
<b>Physical Function</b>	<b>Without any difficulty</b>	<b>With a little difficulty</b>	<b>With some difficulty</b>	<b>With much difficulty</b>	<b>Unable to do</b>
Are you able to do chores such as vacuuming or yard work? <i>pfa11</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Are you able to go up and down stairs at a normal pace? <i>pfa21</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Are you able to go for a walk of at least 15 minutes? <i>pfa23</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Are you able to run errands and shop? <i>pfa53</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
<i>PROMIS 29 v2.1 Physical Function T-Score Variable: pftscore</i>					
<b>Anxiety</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
<b>In the past 7 days...</b>					
I felt fearful <i>edanx01</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I found it hard to focus on anything other than my anxiety <i>edanx40</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My worries overwhelmed me <i>edanx41</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt uneasy <i>edanx53</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS 29 v2.1 Anxiety T-Score Variable: anxtscore*

<b>Depression</b> In the past 7 days...	Never	Rarely	Sometimes	Often	Always
I felt worthless eddep04	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt helpless eddep06	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt depressed eddep29	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt hopeless eddep41	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<i>PROMIS 29 v2.1 Depression T-Score Variable: deptscore</i>					
<b>Fatigue</b> During the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel fatigued hi7	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I have trouble starting things because I am tired an3	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
How run down did you feel on average? fatexp41	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How fatigued were you on average? fatexp40	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<i>PROMIS 29 v2.1 Fatigue T-Score Variable: fattscore</i>					
<b>Sleep Disturbance</b> In the past 7 days...	Very poor	Poor	Fair	Good	Very good
My sleep quality was sleep109	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
My sleep was refreshing sleep116	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I had a problem with my sleep sleep20	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I had difficulty falling asleep sleep44	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<i>PROMIS 29 v2.1 Sleep Disturbance T-Score Variable: pftscore</i>					
<b>Ability to Participate in Social Roles and Activities</b>	Never	Rarely	Sometimes	Usually	Always
I have trouble doing all of my leisure activities with others srpper11	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I have trouble doing all of the family activities that I want to do srpper18	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I have trouble doing all of my usual work (include work at home) srpper23	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I have trouble doing all of the activities with friends that I want to do srpper46	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

*PROMIS 29 v2.1 Ability to Participate in Social Roles T-Score Variable: socroltscore*

<b>Pain Interference</b> In the past 7 days...	<b>Not at all</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Quite a bit</b>	<b>Very much</b>
How much did pain interfere with your day to day activities? <b>painin9</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How much did pain interfere with work around the home? <b>painin22</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How much did pain interfere with your ability to participate in social activities? <b>painin31</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How much did pain interfere with your household chores? <b>painin34</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS 29 v2.1 Pain Interference T-Score Variable: painintscore*

<b>Pain Intensity</b> In the past 7 days...											
How would you rate your pain on average?... <b>global07</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
	<b>No pain</b>								<b>Worst pain imaginable</b>		

“In order to understand if and how a burn injury changes people’s satisfaction with their sex life, we ask a few questions about sexual function. Everybody can answer these questions. If you did not have any sexual activity in the past 30 days, please rate how satisfied you are with no sexual activity.”

**Please respond to each item by marking one box per row.**

<b>In the past 30 days...</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Quite a bit</b>	<b>Very</b>
How satisfied have you been with your sex life? <b>sfsat101</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>In the past 30 days...</b>	<b>None</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Quite a bit</b>	<b>Very much</b>
How much pleasure has your sex life given you? <b>sfsat102</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Sexual Function and Satisfaction T-Score Variable: sfsattscore*

**Interviewer Instructions:** If the participant **had a hand burn**, please complete the next 4 questions. If they **did NOT have a hand burn**, please move on to Section 7 on the next page.

**Please respond to each item by marking one box per row.**

<b>Upper Extremity</b>	<b>Without any difficulty</b>	<b>With a little difficulty</b>	<b>With some difficulty</b>	<b>With much difficulty</b>	<b>Unable to do</b>
Are you able to cut your food using utensils? pfa20	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Are you able to open a can with a hand can opener? pfa28	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Are you able to button your shirt? pfa54	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Are you able to pick up coins from a table top? pfb21r1	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

*PROMIS Upper Extremity 2.0 4a T-Score Variable: upextscore*

**Interviewer instructions:** Write in 88 for refused or 99 for unknown for this section.

### Section 7

**Please respond to each question or statement by marking one box per row.**

<b>Lately...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
1. Because of my injury, some people avoided me. nqstg02	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Because of my injury, I felt left out of things. nqstg04	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Because of my injury, people avoided looking at me. nqstg08	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I felt embarrassed about my injury. nqstg16	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Because of my injury, some people seemed uncomfortable with me. nqstg01	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. I felt embarrassed because of my physical limitations. nqstg17	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Because of my injury, people were unkind to me. nqstg05	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Some people acted as though it was my fault I have this injury. nqstg21	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*Neuro-QOL Stigma SF T-Score Variable: nqstgtscore*

**Section 8** *Interviewer instructions: Write in 88 for refused or 99 for unknown for this section***Please answer thinking of your burn wounds/scars RIGHT NOW**

How bothered are you about...	Not at all	A little	Quite a bit	A lot
...how your wounds/scars look when they are not covered up (for example without clothes or makeup) <b>care_1</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
...how noticeable your wounds/scars are to other people <b>care_2</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
...how your wounds/scars look overall <b>care_3</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

*CARe Burn Wound Scar Dissatisfaction Total Score Variable: care\_tot*

**Section 9**

This section asks about alcohol use in the past year (*Or, since your last research study questionnaire, if your burn was less than a year ago*).

If the participant says they did not drink alcohol in the past year, **mark this box**  and then skip to Section 10, below

*If this box is marked, the rest of the variables are coded as 77=Not applicable*

In the past year...(*Or, since your last research study questionnaire, if the burn was less than a year ago*).

1. Have you felt you needed to cut down on your drinking? <b>cageetohfup1</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown
2. Have people annoyed you by criticizing your drinking? <b>cageetohfup2</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown
3. Have you ever felt guilty about drinking? <b>cageetohfup3</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown
4. Have you ever felt you needed a drink first thing in the morning (eye-opener) to steady your nerves or to get rid of a hangover? <b>cageetohfup4</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown

**Section 10**

This section asks about drug use in the past year (*Or, since your last research study questionnaire, if your burn was less than a year ago*).

If the participant says they did not use drugs in the past year, **mark this box**  and then skip to Section 11 on the next page

*If this box is marked, the rest of the variables are coded as 77=Not applicable*

The questions in this section are asking about use of drugs like crack or heroin; or about prescription drugs like pain killers or stimulants that were not prescribed to you; or chemicals you might have inhaled or 'huffed'. We also want to know if sometimes you took more than you should have of any drugs that have been prescribed to you.

In the past year...(*Or, since your last research study questionnaire, if the burn was less than a year ago*).

1. Have you felt you needed to cut down on your drug use? <b>cagedrug1fup</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown
2. Have people annoyed you by criticizing your drug use? <b>cagedrug2fup</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown
3. Have you ever felt guilty about your drug use? <b>cagedrug3fup</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown
4. Have you ever felt you needed to use drugs first thing in the morning (eye-opener) to steady your nerves or to get rid of a hangover? <b>cagedrug4fup</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	88/Refused 99/Unknown

**Variable notes:**

For these two variables, the summary variable, "etohabufup" and "drugabufup", is coded as a yes =1 if the participant answered two or more of these questions with "yes" (CAGE=2, 3, or 4). The summary variables are coded as "No"=2 if the participant answered 1 or no questions with "yes" (CAGE=0 or 1).

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section I I</b>					
Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then mark circle one of the numbers to the right to indicate how much you have been bothered by that problem in the <u>past month</u> .					
<b>In the past month, how much were you bothered by:</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Moderately</b>	<b>Quite a bit</b>	<b>Extremely</b>
1. Repeated, disturbing, and unwanted memories of the stressful experience? <b>pcl5_1</b>	0	1	2	3	4
2. Repeated, disturbing dreams of the stressful experience? <b>pcl5_2</b>	0	1	2	3	4
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)? <b>pcl5_3</b>	0	1	2	3	4
4. Feeling very upset when something reminded you of the stressful experience? <b>pcl5_4</b>	0	1	2	3	4
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)? <b>pcl5_5</b>	0	1	2	3	4
6. Avoiding memories, thoughts, or feelings related to the stressful experience? <b>pcl5_6</b>	0	1	2	3	4
7. Avoiding external reminders of the stressful experience (for example, people, places, <b>pcl5_7</b> conversations, activities, objects, or situations)?	0	1	2	3	4
8. Trouble remembering important parts of the stressful experience? <b>pcl5_8</b>	0	1	2	3	4
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be <b>pcl5_9</b> trusted, the world is completely dangerous)?	0	1	2	3	4
10. Blaming yourself or someone else for the <b>pcl5_10</b> stressful experience or what happened after it?	0	1	2	3	4
11. Having strong negative feelings such as fear, horror, anger, guilt, or shame? <b>pcl5_11</b>	0	1	2	3	4
12. Loss of interest in activities that you used to enjoy? <b>pcl5_12</b>	0	1	2	3	4
13. Feeling distant or cut off from other people? <b>pcl5_13</b>	0	1	2	3	4
14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)? <b>pcl5_14</b>	0	1	2	3	4

*PCL-5 Total Severity Score Variable: pcl5\_tot  
PCL-5 Cluster B Severity Score Variable: pcl5\_clb  
PCL-5 Cluster C Severity Score Variable: pcl5\_clc  
PCL-5 Cluster D Severity Score Variable: pcl5\_cld  
PCL-5 Cluster E Severity Score Variable: pcl5\_cle  
PCL-5 DSM Provisional Diagnosis Variable: plc5\_dsm*

In the past month, how much were you bothered by:	Not at all	A little bit	Moderately	Quite a bit	Extremely
15. Irritable behavior, angry outbursts, or acting aggressively? <b>pcl5_15</b>	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm? <b>pcl5_16</b>	0	1	2	3	4
17. Being “superalert” or watchful or on guard? <b>pcl5_17</b>	0	1	2	3	4
18. Feeling jumpy or easily startled? <b>pcl5_18</b>	0	1	2	3	4
19. Having difficulty concentrating? <b>pcl5_19</b>	0	1	2	3	4
20. Trouble falling or staying asleep? <b>pcl5_20</b>	0	1	2	3	4

Section 12	
<b>Currently:</b>	
1. Who usually looks after your personal finances, such as banking and paying bills? <b>cia2</b>	88/Refused 99/Unknown
<input type="checkbox"/> 1. Yourself alone <input type="checkbox"/> 2. Yourself and someone else <input type="checkbox"/> 3. Someone else	
<b>Approximately how many times a month do you usually participate in the following activities outside of your home?</b>	
2. Shopping <b>ci3</b>	88/Refused 99/Unknown
<input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	
3. Leisure activities such as movies, sports, and restaurants. <b>ci4</b>	88/Refused 99/Unknown
<input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	
4. Visiting friends or relatives <b>ci5</b>	88/Refused 99/Unknown
<input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	
5. When you participate in leisure activities do you usually do this alone or with others?	88/Refused 99/Unknown
<input type="checkbox"/> 1. Mostly alone <b>ci6</b> <input type="checkbox"/> 2. Mostly with friends who have burn injuries <input type="checkbox"/> 3. Mostly with family members <input type="checkbox"/> 4. Mostly with friends who do not have burn injuries <input type="checkbox"/> 5. With a combination of family and friends <input type="checkbox"/> 77. Not applicable (no leisure activities)	
6. Do you have a best friend with whom you confide? <b>ci7</b>	
<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 88. Refused <input type="checkbox"/> 99. I don't know	

Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.

<b>Section 13</b>							
Here are 4 statements with which you may agree or disagree. Using a scale where 1 represents you strongly disagree and 7 represents that you strongly agree, indicate your agreement with each item by the appropriate choice Please be open and honest in your response.							
	Strongly disagree =1	Disagree =2	Slightly disagree =3	Neither agree nor disagree =4	Slightly agree =5	Agree =6	Strongly agree =7
1. In most ways my life is close to ideal: <b>sl1</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
2. The conditions of my life are excellent: <b>sl2</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
3. I am satisfied with my life: <b>sl3</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
4. So far, I have gotten the <b>sl4</b> important things I want in life:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.

<b>Section 14</b>						
These are some questions about ways people sometimes change after difficult events. Indicate for each of the next statements the degree to which this change occurred in your life as a result of your burn injury, using these response categories: 0 = I did not experience this change as a result of my burn injury 1 = I experienced this change to a very small degree as a result of my burn injury 2 = I experienced this change to a small degree as a result of my burn injury 3 = I experienced this change to a moderate degree as a result of my burn injury 4 = I experienced this change to a great degree as a result of my burn injury 5 = I experienced this change to a very great degree as a result of my burn injury						
	<b>I did not experience this change</b>	<b>To a very small degree</b>	<b>To a small degree</b>	<b>To a moderate degree</b>	<b>To a great degree</b>	<b>To a very great degree</b>
1. I changed my priorities about what is important in life. <b>ptgi_1</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I have a greater appreciation for the value of my own life. <b>ptgi_2</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I am able to do better things with my life. <b>ptgi_3</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I have a better understanding of spiritual matters. <b>ptgi_4</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I have a greater sense of closeness with others. <b>ptgi_5</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	I did not experience this change	To a very small degree	To a small degree	To a moderate degree	To a great degree	To a very great degree
6. I established a new path for my life. <b>ptgi_6</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. I know better that I can handle difficulties. <b>ptgi_7</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. I have a stronger religious faith. <b>ptgi_8</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. I've discovered that I'm stronger than I thought I was. <b>ptgi_9</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. I learned a great deal about how wonderful people are. <b>ptgi_10</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*Post Traumatic Growth Inventory Total Score Variable: ptgitot*

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section 15</b>					
Please respond to all questions. Please mark one box per row.					
<b>Please rate how well each statement describes you right now.</b>	Not at all =1	A little bit =2	=3 Somewhat	=4 Quite a bit	=5 Very much
1. I maintain a positive outlook even in bad circumstances. <b>uwresil4</b>	<input type="checkbox"/>				
2. When something happens that makes me feel stressed, I usually calm down quickly. <b>uwresil10</b>	<input type="checkbox"/>				
3. When something stressful happens, I keep going. <b>uwresil71</b>	<input type="checkbox"/>				
4. When things go wrong in my life, I can pick myself up and start again. <b>uwresil74</b>	<input type="checkbox"/>				

*UW Resilience Scale T-Score Variable: uwresiltscore*



<p><b>7. Approximately what was your family’s total income for the last full year (total income of all family members living with you in your household)? (in U.S. dollars)</b> <span style="color: red;">hinccatfup</span></p> <p> <input type="checkbox"/> 1. Less than \$25,000  <input type="checkbox"/> 2. \$25,000-\$49,999  <input type="checkbox"/> 3. \$50,000-\$99,999  <input type="checkbox"/> 4. \$100,000-\$149,999  <input type="checkbox"/> 5. \$150,000-\$199,999  <input type="checkbox"/> 6. \$200,000 or more  <input type="checkbox"/> 7. Living outside the United States  <input type="checkbox"/> 77. Not applicable (e.g., living in an institution)  <input type="checkbox"/> 88. Prefer not to answer         </p>	<div style="border: 1px solid black; padding: 2px; text-align: center;">99/Unknown</div> <p style="font-size: small; color: blue;">Variable notes: In 2022 the wording of this variable was changed from "household total income" to "family's total income".</p>
<p><b>8. How many people are in your household?</b> <span style="color: red;">numhsfup</span></p>	<div style="border: 1px solid black; padding: 2px; text-align: center;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; text-align: center;">99/Unknown</div>
<p><b>9. In the past year, how many months did you work for pay?</b> <span style="color: red;">mrjobfup</span> (fill in # of months)</p> <p><input type="checkbox"/> Don't know =99</p>	<div style="border: 1px solid black; padding: 2px; text-align: center;">88/Refused</div>
<p><b>10. What is your primary occupation (or what was your primary occupation the last time you worked, if the answer to the above was less than 1 month)?</b></p> <p style="text-align: center;"><b>Occupation:</b> <span style="color: red;">occfup (text field)</span> _____ (not name of company)</p>	<div style="border: 1px solid black; padding: 2px; text-align: center;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; text-align: center;">99/Unknown</div>
<p><u>Occupation Categories [for staff use only]</u> <span style="color: red;">occodefup</span></p> <p>1 - Executive, Administrative, And Managerial, 2 - Professional Specialty, 3 - Technicians And Related Support , 4 – Sales, 5 - Administrative Support Including Clerical, 6 - Private Household, 7 - Protective Service, 8 - Service, Except Protective And Household, 9 - Farming, Forestry, And Fishing, 10 - Precision Production, Craft, And Repair, 11 - Machine Operators, Assemblers, And Inspectors, 12 - Transportation And Material Moving, 13 - Handlers, Equipment Cleaners, Helpers, And Laborers, 14 - Military Occupations</p>	
<p><b>11. What is your current employment status? (Choose only one)</b> <span style="color: red;">employ_fup</span></p> <p> <input type="checkbox"/> 1. Working <span style="font-size: 2em;">→</span>  <input type="checkbox"/> 2. Not working (looking for work)  <input type="checkbox"/> 3. Not working (<u>not</u> looking for work)  <input type="checkbox"/> 4. Homemaker/caregiver  <input type="checkbox"/> 5. Volunteer  <input type="checkbox"/> 6. Retired         </p> <p style="font-size: x-small; color: blue;">Variable notes: Old variable was named "employfu". Wording changed with shift to new forms in 2015 from "current employment status" to "what is your current employment status?" Response options changed from one category, "not working", to two categories, "not working (looking for work)" and "not working (not looking for work)". The response category 8, "N/A, 0-4 age group" removed due to shift to separation of pediatric forms. The use of the code for 2, "not working", is no longer in use in the new data collection forms. The data that was collected as 2 on the old forms is stored in the database as "66-"Not working" on old forms".</p>	<p>(If the participant was working) About how many <u>hours a week</u> do you work for pay?</p> <p style="text-align: center;"><span style="color: red;">hpayfup</span> _____</p> <p style="text-align: center;">(fill in # of hours)</p> <p>If the participant hadn't already returned to work/school before their last research study questionnaire but they are working now, What was your first date to return to work/school since your injury? (Please take your best guess if you don't know the exact date):</p> <p style="text-align: center;">____ / ____ / ____</p> <p style="text-align: right; color: red; font-size: small;">rtrndat</p>
<div style="border: 1px solid black; padding: 2px; text-align: center;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; text-align: center;">99/Unknown</div>	<div style="border: 1px solid black; padding: 2px; text-align: center;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; text-align: center;">99/Unknown</div> <p style="font-size: x-small; color: blue;">Variable notes: Entered into Patient Status form</p>

**Interviewer Instructions:** *If the participant is not currently working, skip to #14, below.*

12. (If you are currently working,) Have you received any work accommodations from your employer due to your burn injury? This could include a change in procedure or schedule, a modification to your work site, or assistive equipment. **employacc**

- 1. No, my employer was not asked for accommodations and I did not receive any
- 2. No, my employer was asked for accommodations, but the request was denied
- 3. Yes, my employer was asked for accommodations and I received some or all accommodations asked for
- 4. Yes, my employer provided accommodations without being asked.
- 99. I don't know

88/Refused

99/Unknown

**Interviewer Instructions:** *Skip#13 and move on to #14 if the participant declined to answer the household income question or if the participant is a one-person household (fill in income from household question if the participant is a one-person household).*

13. Approximately what was your individual income for the past full year? (in U.S. dollars) **iinccatfup**

- 1. Less than \$25,000
- 2. \$25,000-\$40,999
- 3. \$41,000-\$55,999
- 4. \$56,000-\$70,999
- 5. \$71,000-\$85,999
- 6. \$86,000-\$100,000
- 7. Greater than \$100,000
- 8. Living outside the United States
- 77. Not applicable (no individual income)
- 88. Prefer not to answer

99/Unknown

<p style="text-align: right;"><b>aschoolfu</b></p> <p>14. What is your current school status?</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. In school</li> <li><input type="checkbox"/> 2. Not in school</li> </ul>	<p style="text-align: right;"><b>whynotfu</b></p> <p><i>If you are not working or going to school, why not?</i></p> <ul style="list-style-type: none"> <li>77 Not applicable (working or going to school)</li> <li><input type="checkbox"/> 1 Burn related</li> <li><input type="checkbox"/> 2 Other Medical problems</li> <li><input type="checkbox"/> 3 Problems with employer</li> <li><input type="checkbox"/> 4 Emotional/social reasons</li> <li><input type="checkbox"/> 5 Legal reasons/jail</li> <li><input type="checkbox"/> 6 Substance abuse</li> <li><input type="checkbox"/> 7 Personal choice</li> <li><input type="checkbox"/> 8 Other</li> <li><input type="checkbox"/> 9 Retired</li> <li><input type="checkbox"/> 10 Homemaker/caregiver</li> <li><input type="checkbox"/> 11 Unemployed but actively seeking employment</li> <li><input type="checkbox"/> 99 I don't know</li> </ul>
	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; display: inline-block;">99/Unknown</div>	

15. How many years of education have you completed? **educfup**  
 (If you have not graduated from high school, please indicate the number of years spent in school. If you have at least a high school diploma, please indicate the highest degree earned or worked toward post-high school. In other words, what is the highest level of education you have completed?)

1. 1 year or less  
 2. 2 years  
 3. 3 years  
 4. 4 years  
 5. 5 years  
 6. 6 years  
 7. 7 years  
 8. 8 years  
 9. 9 years  
 10. 10 years  
 11. 11 or 12 years; no diploma  
 12. High school diploma or equivalent (ie, GED) *Variable notes: GED added to this option in 2022*  
 13. Work towards Associate's degree, vocational degree, or trade school diploma/cert.  
 14. Associate's degree, vocational degree, or trade school diploma/certificate  
 15. Work towards Bachelor's degree  
 16. Bachelor's degree  
 17. Work towards Master's degree  
 18. Master's degree  
 19. Work towards doctorate level degree  
 20. Doctoral level degree  
 66. Other

88/Refused  
 99/Unknown

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16. Are you currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)

1. I am not receiving disability income **disincfup\_\_1**  
 2. Social Security Disability **disincfup\_\_2**  
**disincfup\_\_3**  3. Private long term insurance disability income  
**disincfup\_\_4**  4. Supplemental security income (SSI)  
 5. Worker's compensation **disincfup\_\_5**  
**disincfup\_\_6**  6. Other (please specify) **disincfupo (text field)**  
 99. I don't know **disincfup\_\_99**

*Variable notes:*  
 For each variable, 0 = "no"(not checked) and 1 = "yes" (checked). **disincfup\_\_88**

88/Refused

If yes, are you receiving disability income due to your burn injury? **disincbrn**

1. Yes, I am receiving disability income due to my burn injury  
 2. No, I am not receiving disability income due to my burn injury  
 77. Not applicable (not receiving disability income)  
 99. I don't know

88/Refused

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17. Do you currently have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? **physprobup**

1. Yes  
 2. No  
 99. I don't know

88/Refused

<p><b>18. Who is the primary sponsor of your care currently, or who is paying for the majority of your burn care costs? (Choose only one) <span style="color: red;">payfup</span></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. Medicare</li> <li><input type="checkbox"/> 2. Medicaid (DSHS)</li> <li><input type="checkbox"/> 3. Private insurance/HMO/PPO/Pre-paid/Managed</li> <li><input type="checkbox"/> 4. Worker’s compensation (L&amp;I)</li> <li><input type="checkbox"/> 6. Champus/Tri-Care</li> <li><input type="checkbox"/> 7. Self-pay or indigent (public support)</li> <li><input type="checkbox"/> 9. VA</li> <li><input type="checkbox"/> 10. Other</li> <li><input type="checkbox"/> 11. Philanthropy (private support or private foundation or Shriners hospital)</li> <li><input type="checkbox"/> 77. Not applicable (no burn care costs)</li> <li><input type="checkbox"/> 99. I don’t know</li> </ul>	<p><u>Variable Notes:</u>                  In 2018, the categories HMO/PPO/Pre-paid/Managed Care and Private insurance (previously categories 3 and 5) were collapsed into one broader category                  --In 2018, the categories indigent and self-pay (previously categories 7 and 8) were collapsed into one broader category                  --In 2018 clarification was added to #11 that it is the category to select when care was paid for by Shriners.                  --When changes were made in 2018, existing data was pulled and archived so categories that were collapsed could be expanded with historical data, if necessary.</p>
<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>	
<p><b>19. Have you ever served in the military? <span style="color: red;">milfup</span></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. No</li> <li><input type="checkbox"/> 2. Yes</li> </ul>	<div style="border: 1px solid black; padding: 2px; display: inline-block; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; display: inline-block;">99/Unknown</div>

Length of interview: length \_\_\_\_\_

“Is there anything else you would like to tell us? comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

“Thank you very much for sharing your experiences with us!”

## BMS Pediatric Self Report Interview 14-17 Form I: Research Staff Instructions

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

<b>Form I Administration:</b>		
<p><b>What is the method of administration of this form?</b> <i>admin</i></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>	<p><b>What is the language of administration of this form?</b> <i>language</i></p> <p><input type="checkbox"/> 1. English</p> <p><input type="checkbox"/> 2. Spanish</p>	<p><b>Checklist of forms:</b> <b>Mark when each is complete</b> <i>status</i></p> <p><input type="checkbox"/> 1. Patient Status Form</p> <p><input type="checkbox"/> 2. Medical Record Abstraction Form</p> <p><input type="checkbox"/> 3. Form I</p>

**Introduction script** (Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

"Thank you for agreeing to participate in this study. The aim of the study is to learn about how young people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I'll be asking questions about your burn injury, your health, and other questions about you and people around you. Some questions ask about what things were like before your burn injury, other questions are about your health now. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip." Please let me know at any time if you have any questions."

## Burn Model System Hospital Discharge Survey

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ disintdate

We're going to go ahead and get started."

### Section I

**Instructions: Please answer each question with a "yes" or "no".  
If you answer "yes", then please indicate to what extent this problem affects your daily activities using these responses:**

1 <i>Not at all</i>	2 <i>To a very small extent</i>	3 <i>To a small extent</i>	4 <i>To a moderate extent</i>	5 <i>To a fairly great extent</i>	6 <i>To a great extent</i>	7 <i>To a very great extent</i>				
Do you have problems... Problem?				1	2	3	4	5	6	7
1. Seeing? <span style="color: red;">chcself1, chcself1a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hearing? <span style="color: red;">chcself2, chcself2a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Learning and understanding? <span style="color: red;">chcself3, chcself3a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <span style="color: red;">chcself4, chcself4a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Controlling emotions or behavior? <span style="color: red;">chcself5, chcself5a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. with Seizures or epilepsy? <span style="color: red;">chcself6, chcself6a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <span style="color: red;">chcself7, chcself7a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. with Teeth and gums? <span style="color: red;">chcself8, chcself8a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. with Digestion (eg reflux, vomiting, or constipation)? <span style="color: red;">chcself9, chcself9a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. with Type 1 or Type 2 diabetes? <span style="color: red;">chcself10, chcself10a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. with Growth? <span style="color: red;">chcself11, chcself11a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Sleeping? <span style="color: red;">chcself12, chcself12a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. with Repeated infections? <span style="color: red;">chcself13, chcself13a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. with Breathing (eg asthma)? <span style="color: red;">chcself14, chcself14a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)? <span style="color: red;">chcself15, chcself15a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)? <span style="color: red;">chcself16, chcself16a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)? <span style="color: red;">chcself17, chcself17a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain? <span style="color: red;">chcself18, chcself18a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you have any other health problems? <span style="color: red;">chcself19</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem: <span style="color: red;">chcself19ot (text field)</span>					

### Pre-Injury History Section

“The next section of questions is about your life and your situation before the injury. Your answers will help us understand problems related to the injury. You’ll also be asked similar questions about after your burn injury later in the interview.”

#### Section 2

Indicate how much you agree or disagree:

In the four weeks before my burn...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	
1. My life was going well. pa066pre	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
2. My life was just right. pa067pre	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
3. I had a good life. pa070pre	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
4. I had what I wanted in life. pa071ore	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown

NIH General Life Satisfaction Self-Report 13-17 T-Score Variable: *tblgstscore13\_17\_pre*

#### Section 3

During the 4 weeks before your burn:

1. Did you take responsibility for personal grooming when asked? cip2\_pre

1. Often

2. Sometimes

3. Never

88/Refused  
99/Unknown

Approximately how many times during the 4 weeks before the burn did you participate in the following activities outside of your home?

2. Shopping ci3\_pre

1. Never

2. 1-4 times

3. 5 or more times

88/Refused  
99/Unknown

3. Leisure activities such as movies, sports, and restaurants. ci4\_pre

1. Never

2. 1-4 times

3. 5 or more times

88/Refused  
99/Unknown

4. Visiting friends or relatives ci5\_pre

1. Never

2. 1-4 times

3. 5 or more times

88/Refused  
99/Unknown

During the 4 weeks before your burn:	
5. When you participated in leisure activities did you usually do this alone or with others? <input type="checkbox"/> 1. Mostly alone <b>ci6_pre</b> <input type="checkbox"/> 3. Mostly with family members <input type="checkbox"/> 4. Mostly with friends <input type="checkbox"/> 5. With a combination of family and friends <input type="checkbox"/> 77. Not applicable (no leisure activities)	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
6. Did you have a best friend with whom you confided? <b>ci7_pre</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>

*CIQ Social Integration Subscale Total Score Variable: ciqsic\_pre*

Section 4	
1. In the month before your burn injury did you take <u>prescription</u> medication for pain on a regular basis? <b>pmed_pre</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
<b>In the past 12 months...</b>	
2. In the past 12 months, did you take medication for being worried, tense, or anxious? <input type="checkbox"/> 1. Yes <b>imed_pre</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
3. In the past 12 months, did you take medication for being sad, empty, or depressed? <input type="checkbox"/> 1. Yes <b>wmed_pre</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
4. Did you receive psychological therapy or counseling in the last 12 months? <input type="checkbox"/> 1. Yes <b>psychtr</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>

Section 5	
1. Before your burn injury, where were you living? (Choose only one) <b>resdenc</b> <input type="checkbox"/> 1. Private residence <input type="checkbox"/> 2. Nursing home <input type="checkbox"/> 3. Adult home <input type="checkbox"/> 4. Correctional institution <input type="checkbox"/> 5. Hotel/motel <input type="checkbox"/> 6. Homeless <input type="checkbox"/> 7. Hospital	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p><i>Variable notes:</i>            In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.</p>	

<p>2. What was your zip code at the time of your burn injury? <u>zip_pre</u> _____</p> <p><input type="checkbox"/> 1 Not applicable (not living in U.S.) <input type="checkbox"/> 2 Not applicable (homeless)          (code 99999 for unknown) <span style="float: right; color: red;">Checkboxes correspond to variable "zippremiss"</span></p>	
<p>3. Who were you living with before your burn injury? (Choose all that apply)</p> <p><input type="checkbox"/> 4. Parent or step-parent <span style="color: red;">livinga__4</span> <span style="float: right; color: blue;">Variable notes:</span></p> <p><input type="checkbox"/> 5. Other relative (siblings, grandparents) <span style="color: red;">livinga__5</span> <span style="float: right; color: blue;">For each variable, 0 =</span></p> <p><input type="checkbox"/> 6. Others, not part of family <span style="color: red;">livinga__6</span> <span style="float: right; color: blue;">"no"(not checked) and 1</span></p> <p><input type="checkbox"/> 7. Guardian <span style="color: red;">livinga__7</span> <span style="float: right; color: blue;">= "yes" (checked)</span></p> <div style="float: right; border: 1px solid black; padding: 2px; margin-top: 10px;">             88/Refused  <span style="color: red;">livinga__88</span>              99/Unknown  <span style="color: red;">livinga__99</span> </div>	
<p>4. Were you enrolled in school at the time of your burn injury? <span style="color: red;">schoolstat</span></p> <p><input type="checkbox"/> 1. Yes, in school</p> <p><input type="checkbox"/> 2. No, not in school</p> <div style="margin-top: 20px; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">             88/Refused              99/Unknown         </div>	<p>If you were not enrolled in school at the time of your burn injury, why not? <span style="color: red;">whynot</span></p> <p><input type="checkbox"/> 2 Medical problems</p> <p><input type="checkbox"/> 4 Emotional/social reasons</p> <p><input type="checkbox"/> 5 Legal reasons/jail</p> <p><input type="checkbox"/> 6 Substance abuse</p> <p><input type="checkbox"/> 7 Personal choice</p> <p><input type="checkbox"/> 8 Other</p> <p><input type="checkbox"/> 77 Not applicable (going to school)</p> <p><input type="checkbox"/> 99 I don't know</p> <div style="float: right; border: 1px solid black; padding: 2px; margin-top: 10px;">             88/Refused         </div>
<p>5. Are you ahead, at the same level, or behind the grade you should be in for your age group? <span style="color: red;">gradelvl</span></p> <p><input type="checkbox"/> 1. Above the grade level I should be in for my age</p> <p><input type="checkbox"/> 2. At the grade level I should be in for my age</p> <p><input type="checkbox"/> 3. Lower than the grade level I should be in for my age</p> <p><input type="checkbox"/> 77. Not applicable</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="float: right; border: 1px solid black; padding: 2px; margin-top: 10px;">             88/Refused         </div>	
<p>6. In school, have you ever been classified as a special education student? <span style="color: red;">speducdis</span></p> <p><input type="checkbox"/> 1. Yes =2</p> <p><input type="checkbox"/> 2. No =1</p> <p><input type="checkbox"/> 77. Not applicable</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="float: right; border: 1px solid black; padding: 2px; margin-top: 10px;">             88/Refused         </div>	
<p>7. Before your burn injury, did you have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? <span style="color: red;">physprobpre</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="float: right; border: 1px solid black; padding: 2px; margin-top: 10px;">             88/Refused         </div>	
<p>8. Before your burn injury, were you ever told by a doctor that you had any of the following psychological issues (choose all that apply)? <span style="color: red;">psychlist</span></p> <p><input type="checkbox"/> 0. None/no psychological issues</p> <p><input type="checkbox"/> 1. Depression</p> <p><input type="checkbox"/> 2. Bipolar disorder</p> <p><input type="checkbox"/> 3. Anxiety</p> <p><input type="checkbox"/> 4. Post-Traumatic Stress Disorder (PTSD)</p> <p><input type="checkbox"/> 5. Schizophrenia/psychotic disorder</p> <p><input type="checkbox"/> 6. Other, please explain: <span style="color: red;">psychlistot (text field)</span> _____</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="float: right; border: 1px solid black; padding: 2px; margin-top: 10px;">             88/Refused         </div> <div style="float: right; color: blue; margin-top: 10px; font-size: small;"> <u>Variable notes:</u>              There are two other variables in the database, psychlist2 and psychlist3 with the same coding in case more than one or two issues were selected.         </div>	

## Post-Injury History Section

“All the questions you just answered were about you and the time before your burn injury. Next are some questions about you and your burn injury. As a reminder, some of these questions can feel repetitive but it’s part of the research process. Thank you for your patience.”

### Section 6

In the past 7 days, or since your burn if you were injured less than 7 days ago...

How would you rate your pain on average?...	<input type="checkbox"/>										
<i>global07_dis</i>	0	1	2	3	4	5	6	7	8	9	10
88/Refused 99/Unknown	<b>No pain</b>										<b>Worst pain imaginable</b>

### Section 7

1. Are you of Hispanic, Latino, or Spanish Origin? *ethnicity*

1. Yes, Hispanic, Latino, or Spanish origin  
 2. No, not of Hispanic, Latino, or Spanish origin  
 88. Prefer not to answer

2. What is your race? *race*

1. African-American or Black  
 2. Asian  
 3. White  
 4. American Indian/Alaskan Native  
 5. Native Hawaiian or Other Pacific Islander  
 6. More than one race ((please specify): *racemto (text field)*  
 7. Some other race (please specify): *raceotr (text field)*  
 88. Prefer not to answer

### Section 8

“This is the last section of the survey”

1. After your hospital discharge, where are/will you be living? (Choose only one) *dislivisit*

1. Private residence  
 2. Nursing home  
 4. Correctional institution  
 5. Hotel/motel  
 6. Homeless  
 7. Hospital  
 99. I don't know

88/Refused

Variable notes:

In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.

<p>2. Who will you be living with after hospital discharge? (Choose all that apply)</p> <p><input type="checkbox"/> 4. Parent or step-parent livhsdis__4</p> <p><input type="checkbox"/> 5. Other relative (siblings, grandparents) livhsdis__5</p> <p><input type="checkbox"/> 6. Others, not part of family livhsdis__6</p> <p><input type="checkbox"/> 7. Guardian livhsdis__7</p> <p><input type="checkbox"/> 99. I don't know livhsdis__99</p>	<p>livhsdis__88</p> <div style="border: 1px solid black; padding: 2px; text-align: center;">88/Refused</div> <p><i>Variable notes:</i> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).</p>
<p>3. How many years of education have you completed? educdis</p> <p>(If you have not graduated from high school, please indicate the number of years spent in school. If you have at least a high school diploma, please indicate the highest degree earned or worked toward post-high school. In other words, what is the highest level of education you have completed?)</p> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 5. 5 years</p> <p><input type="checkbox"/> 6. 6 years</p> <p><input type="checkbox"/> 7. 7 years</p> <p><input type="checkbox"/> 8. 8 years</p> <p><input type="checkbox"/> 9. 9 years</p> <p><input type="checkbox"/> 10. 10 years</p> <p><input type="checkbox"/> 11. 11 or 12 years; no diploma</p> <p><input type="checkbox"/> 12. High school diploma or equivalent (ie, GED) (GED added to this option in 2022)</p> <p><input type="checkbox"/> 66. Other</p>	
<p>4. Are you currently receiving <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)</p> <p><input type="checkbox"/> 1. I am not receiving disability income disincdis__1</p> <p><input type="checkbox"/> 2. Social Security Disability disincdis__2</p> <p><input type="checkbox"/> 3. Private long term insurance disability income disincdis__3</p> <p><input type="checkbox"/> 4. Supplemental security income (SSI) disincdis__4</p> <p><input type="checkbox"/> 5. Worker's compensation disincdis__5</p> <p><input type="checkbox"/> 6. Other (please specify) disincdis__6      disincdiso (text field)</p> <p><input type="checkbox"/> 99. I don't know disincdis__99</p>	<p>88/Refused</p> <p>disincdis__88</p> <p><i>Variable notes:</i> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).</p>

Length of interview: \_\_\_\_\_

“Is there anything else you would like to tell us? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you very much for sharing your experiences with us.”

## BMS Pediatric Self Report 13-17 Interview Form II: Research Staff Instructions

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead. Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

<b>Form II Administration:</b>			
<p><b>Follow-up period</b> <i>follow_up</i></p> <p><input type="checkbox"/> 1. 6-month follow-up</p> <p><input type="checkbox"/> 2. 12 month follow-up</p> <p><input type="checkbox"/> 3. 24 month follow-up</p> <p><input type="checkbox"/> 4. 5 year follow-up</p> <p><input type="checkbox"/> 5. 10 year follow-up</p> <p><input type="checkbox"/> 6. 15 year follow-up</p>	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; vertical-align: top; padding: 5px;"> <p><b>What is the method of</b> <i>admin_fup</i> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p> </td> <td style="width: 50%; vertical-align: top; padding: 5px;"> <p><b>What is the language of</b> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. English <i>language_fup</i></p> <p><input type="checkbox"/> 2. Spanish</p> </td> </tr> </table>	<p><b>What is the method of</b> <i>admin_fup</i> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>	<p><b>What is the language of</b> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. English <i>language_fup</i></p> <p><input type="checkbox"/> 2. Spanish</p>
<p><b>What is the method of</b> <i>admin_fup</i> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>	<p><b>What is the language of</b> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. English <i>language_fup</i></p> <p><input type="checkbox"/> 2. Spanish</p>		
<p><b>What is the status of this follow-up assessment?</b> <i>lostfolo</i></p> <p><input type="checkbox"/> 1. Some or all assessment done</p> <p><input type="checkbox"/> 2. Death due to burn related complications (update date and cause of death on Patient Status Form)</p> <p><input type="checkbox"/> 3. Death due to non- burn related complications (update date and cause of death on Patient Status Form)</p> <p><input type="checkbox"/> 4. Unable to locate</p> <p><input type="checkbox"/> 5. Refused this assessment</p> <p><input type="checkbox"/> 6. Unable to test/med comp/incapable of responding</p> <p><input type="checkbox"/> 7. Failed to respond</p> <p><input type="checkbox"/> 8. Did not consent to future assessment/withdrew</p> <p><input type="checkbox"/> 11. Incarcerated</p> <p><input type="checkbox"/> 13. Still in hospital (not discharged yet)</p> <p><input type="checkbox"/> 14. Unable to travel for assessment</p> <p><input type="checkbox"/> 15. Death (unknown causes) (update date and cause of death on Patient Status Form)</p>	<p><b>If follow-up status is "unable to locate," mark the best reason, below:</b> <i>unabletolocate</i></p> <p><input type="checkbox"/> 1. Homeless at previous data collection</p> <p><input type="checkbox"/> 2. International place of residence</p> <p><input type="checkbox"/> 3. Participant is child who was/is in CPS custody or foster care and no contact information is available</p> <p><input type="checkbox"/> 4. No known current contact info</p> <p><input type="checkbox"/> 5. Other reasons</p> <p><input type="checkbox"/> 6. Unable to contact due to Shriners Hospital regulations</p>		

## Burn Model System Follow-up Survey

**Introduction Script** (replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

“Hi my name is \_\_\_\_ and I am calling from \_\_\_\_\_ to ask you some questions about how you have been doing (since your injury)... or (since we last spoke with you on (last follow-up date)). Thank you for continuing to participate in our study. The aim of the study is to learn about how young people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I’ll be asking questions about your burn injury, your health, and other questions about you and people around you. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.” Please let me know at any time if you have any questions.”

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ fup\_date

“As a reminder, your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.”

“We’re going to go ahead and get started.”

### Section I

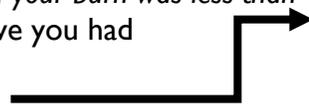
1. Since your last research study questionnaire, have you spoken with other burn survivors to get support for problems related to your burn injury? peersup

88/Refused

1. Yes  
 2. No  
 99. I don’t know

2. To your knowledge, in the last year have you had COVID-19? **covidstat**

Or, since your last research study questionnaire if your burn was less than a year ago, have you had COVID-19?

1. Yes 

2. No

99. I don't know

**88/Refused**

(If yes), What month and year did you have COVID-19?  
(if you've had COVID-19 more than once, provide the month and year of your first illness)

Month: **covidmonth**

Year: **covidyear**

**88/Refused**  
**99/Unknown**

What level of care did you receive for COVID-19? **covidcare**

1. Did not seek medical care

2. Received medical care but was not hospitalized

3. Was hospitalized

In the hospital... (if applicable) **covidvent**

1. I was NOT on a ventilator (breathing machine with tube down your throat)

2. I was on a ventilator

3. I don't know

**88/Refused**

3. Since your last research study questionnaire, have you received any of the following services at home or outpatient?  
(Choose all that apply)

1. No services **services\_\_1**

2. Occupational therapy **services\_\_2**

3. Physical therapy **services\_\_3**

4. Speech language pathology **services\_\_4**

5. Social work **services\_\_5**

6. Psychological services **services\_\_6**

7. Vocational services or child life services **services\_\_7**

99. I don't know **services\_\_99**

**88/Refused**  
**services\_\_88**

*If clarification is needed, say*  
**“Examples of occupational therapy include helping with adjusting to a school environment after injury. Examples of physical therapy include range of motion and walking exercises.”**

Variable notes:  
For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)

**Interviewer Instructions: If the participant didn't receive any services OR if you didn't receive PT/OT, skip to #8 on page 4**

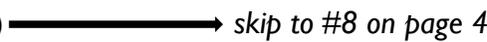
4. If yes to OT and/or PT, How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? (If you don't know exactly, use your best guess) **numther**

1. One

2. 2 to 4

3. 5 to 10

4. More than 10

77. Not applicable (no OT/PT received) 

99. I don't know

**88/Refused**

If yes to OT and/or PT, “Since your last research study questionnaire, where did you receive your outpatient occupational or physical burn therapy?”

5. At the burn center? **ther\_brn\_ctr**

1. Yes

2. No

77. Not applicable (no OT/PT received)

99. I don't know

**88/Refused**

<p>6. At any other facility? <b>ther_otr</b></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused
<p>7. Using telehealth? (for example, meeting with your therapist using video conferencing)</p> <p><input type="checkbox"/> 1. Yes <b>telehlth</b></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused
<p>8. Since your last research study questionnaire, have you had any burn related surgeries (such as surgeries for open wounds or scar management)?</p> <p><input type="checkbox"/> 1. Yes </p> <p><input type="checkbox"/> 2. No <b>surgery_fu</b></p> <p><input type="checkbox"/> 99. I don't know</p>	<p><b>surgout</b></p> <p>(If you <u>did</u> have burn related surgeries) Have you had any burn-related surgeries outside of this clinical center?</p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>

<b>Section 2</b> <b>Instructions: Please answer each question with a "yes" or "no".</b> <b>If you answer "yes", then please indicate to what extent this problem affects your daily activities using these responses:</b> <i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section</i>													
1 Not at all	2 To a very small extent	3 To a small extent	4 To a moderate extent	5 To a fairly great extent	6 To a great extent	7 To a very great extent							
Do you have problems...			Problem?		1	2	3	4	5	6	7		
1. Seeing? <b>chcself1, chcself1a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hearing? <b>chcself2, chcself2a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Learning and understanding? <b>chcself3, chcself3a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <b>chcself4, chcself4a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Controlling emotions or behavior? <b>chcself5, chcself5a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. with Seizures or epilepsy? <b>chcself6, chcself6a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <b>chcself7, chcself7a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. with Teeth and gums? <b>chcself8, chcself8a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. with Digestion (eg reflux, vomiting, or constipation)? <b>chcself9, chcself9a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. with Type 1 or Type 2 diabetes? <b>chcself10, chcself10a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. with Growth? <b>chcself11, chcself11a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Sleeping? <b>chcself12, chcself12a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. with Repeated infections? <b>chcself13, chcself13a</b>			<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have problems...	Problem?	1	2	3	4	5	6	7
14. with Breathing (eg asthma)? <b>chcself14, chcself14a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)? <b>chcself15, chcself15a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)? <b>chcself16, chcself16a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)? <b>chcself17, chcself17a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain? <b>chcself18, chcself18a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you have any other health problems? <b>chcself19</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem: <b>chcself19ot (text field)</b>						

Section 3	
1. Are you <b>currently</b> taking <u>prescription</u> medication for pain on a regular basis? <b>pmed_curr</b>	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know
2. Are you <b>currently</b> taking <u>prescription</u> medication for itch on a regular basis? <b>imed</b>	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know
3. In the <b>past 12 months</b> , did you take medication for being, worried, tense, or anxious? <b>wmed</b>	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know
4. In the past 12 months, did you take medication for being sad, empty, or depressed? <b>smed</b>	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know
5. Since your last research study questionnaire, have you received psychological therapy or counseling due to your burn injury? <b>psychther</b>	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section*

<b>Section 4</b>					
<b>The following questions ask about your appearance:</b>					
	<b>Definitely true = 1</b>	<b>Mostly true = 2</b>	<b>Not sure = 3</b>	<b>Mostly false = 4</b>	<b>Definitely false = 5</b>
1. I feel that the burn is unattractive to others. <b>bodyim_1</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I think people would not want to touch me. <b>bodyim_2</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel unsure of myself among strangers. <b>bodyim_3</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Changes in my appearance have interfered with my relationships. <b>bodyim_4</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section*

<b>Section 5</b>				
<b>This is a list of problems that kids sometimes have after experiencing an upsetting event. Read each one carefully and then choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.</b>				
	<b>Not at all or only at one time=0</b>	<b>Once a week or less/ once in a while=1</b>	<b>2 to 4 times a week/ half the time=2</b>	<b>5 or more times a week/ almost always=3</b>
1. Having upsetting thoughts or images about your burn injury that came into your head when you didn't want them to <b>cpss_1</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Having bad dreams or nightmares <b>cpss_2</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Acting or feeling as if your burn injury was happening again (hearing something or seeing a picture about it and feeling as if I am there again) <b>cpss_3</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc) <b>cpss_4</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Having feelings in your body when you think about or hear about your burn injury (for example, breaking out into a sweat, heart beating fast) <b>cpss_5</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Trying not to think about, talk about, or have feelings about your burn injury <b>cpss_6</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<b>Not at all or only at one time=0</b>	<b>Once a week or less/ once in a while=1</b>	<b>2 to 4 times a week/ half the time=2</b>	<b>5 or more times a week/ almost always=3</b>
7. Trying to avoid activities, people, or places that remind you of your burn injury <small>cpss_7</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Not being able to remember an important part of your burn injury <small>cpss_8</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Having much less interest or doing things you used to do <small>cpss_9</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Not feeling close to people around you <small>cpss_10</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) <small>cpss_11</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Feeling as if your future plans or hopes will not come true (for example, you will not have a job or getting married or having kids) <small>cpss_12</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Having trouble falling or staying asleep <small>cpss_13</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Feeling irritable or having fits of anger <small>cpss_14</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class) <small>cpss_15</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Being overly careful (for example, checking to see who is around you and what is around you) <small>cpss_16</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Being jumpy or easily startled (for example, when someone walks up behind you) <small>cpss_17</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 6***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section***Please respond to each item by marking one box per row.**

In the past 7 days...	1= Never	2= Almost Never	3= Some-times	4= Often	5=Almost always
1. I felt mad pr206r1r	<input type="checkbox"/>				
2. I felt upset pr714r1r	<input type="checkbox"/>				
3. I felt fed up pr5045r1r	<input type="checkbox"/>				
4. I was so angry I felt like throwing something pr2319ar1r	<input type="checkbox"/>				
5. I was so angry I felt like yelling at somebody pr2581r1r	<input type="checkbox"/>				

**Section 7***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section***Please respond to each question or statement by marking one box per row.**

<b>Physical Function</b> In the past 7 days...	With no trouble	With a little trouble	With some trouble	With a lot of trouble	Not able to do
I could do sports and exercise that other kids my age could do pr235r1r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I could get up from the floor pr4124r1r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I could walk up stairs without holding on to anything pr2707r2r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I have been physically able to do the activities I enjoy most pr5023r1r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

<b>Anxiety</b> In the past 7 days...	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost always</b>
I felt like something awful might happen <sup>pr2220r2r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt nervous <sup>pr713r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt worried <sup>pr5044r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I worried when I was at home <sup>pr3459br1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Depressive symptoms</b> In the past 7 days...					
I felt everything in my life went wrong <sup>pr5041r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt lonely <sup>pr711r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt sad <sup>pr228r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to have fun <sup>pr3952ar2r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Fatigue</b> In the past 7 days...					
Being tired made it hard for me to keep up with my schoolwork <sup>pr4239ar2r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I got tired easily <sup>pr2876r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I was too tired to do sports or exercise <sup>pr4241r2r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I was too tired to enjoy the things I like to do <sup>pr4196r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Peer relationships</b> In the past 7 days...					
I felt accepted by other kids my age <sup>pr5018r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I was able to count on my friends <sup>pr5058r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My friends and I helped each other out <sup>pr5055r1r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Other kids wanted to be my friend <sup>pr233r2r</sup>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Pain Interference</b> In the past 7 days...	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost always</b>
I had trouble sleeping when I had pain <span style="color: red;">pr3793r1r</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to pay attention when I had pain <span style="color: red;">pr9004r</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to run when I had pain <span style="color: red;">pr2045r1r</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to walk one block when I had pain <span style="color: red;">pr2049r1r</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Pain Intensity</b> In the past 7 days...										
How bad was your pain on average?...	<input type="checkbox"/>	<input type="checkbox"/>								
<span style="color: red;">pr9033r1</span>	0	1	2	3	4	5	6	7	8	9 10
<input type="checkbox"/> 88/Refused <input type="checkbox"/> 99/Unknown	<b>No pain</b>								<b>Worst pain you can think of</b>	

<b>Section 8</b> <i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section</i>					
<b>Indicate how much you agree or disagree:</b>					
	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1. My life is going well. <span style="color: red;">pa066</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My life is just right. <span style="color: red;">pa067</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I have a good life. <span style="color: red;">pa070</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I have what I want in life. <span style="color: red;">pa071</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Section 9</b>	
<b>Currently:</b>	
1. Do you take personal responsibility for grooming when asked? <span style="color: red;">cip2</span>	<input type="checkbox"/> 88/Refused <input type="checkbox"/> 99/Unknown
<input type="checkbox"/> 1. Often	
<input type="checkbox"/> 2. Sometimes	
<input type="checkbox"/> 3. Never	

Approximately how many times a month do you usually participate in the following activities outside of your home?	
2. Shopping <b>ci3</b> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	88/Refused 99/Unknown
3. Leisure activities such as movies, sports, and restaurants. <b>ci4</b> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	88/Refused 99/Unknown
4. Visiting friends or relatives <b>ci5</b> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	88/Refused 99/Unknown
5. When you participate in leisure activities do you usually do this alone or with others? <input type="checkbox"/> 1. Mostly alone <b>ci6</b> <input type="checkbox"/> 2. Mostly with friends who have burn injuries <input type="checkbox"/> 3. Mostly with family members <input type="checkbox"/> 4. Mostly with friends who do not have burn injuries <input type="checkbox"/> 5. With a combination of family and friends <input type="checkbox"/> 77. Not applicable (no leisure activities)	88/Refused 99/Unknown
6. Do you have a best friend with whom you confide? <b>ci7</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	88/Refused

Section 10 <b>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section</b>						
Please respond to each question or statement by marking one box per row.						
In the past 7 days ...	Never	Almost Never	Sometimes	Often	Almost Always	
I had trouble sleeping when I was itching <b>bmsitch_1</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
I felt angry when I was itching <b>bmsitch_2</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
It was hard for me to pay attention when I was itching <b>bmsitch_4</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
It was hard for me to have fun when I was itching <b>bmsitch_5</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<b>77=N/A</b> (I don't do schoolwork)	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
I had trouble doing schoolwork when I was itching <b>bmsitch_3</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**BMS Itch Interference Self Report Total Score: bmsitchscore\_ped**

**Section 11***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>No days</b>	<b>1 day</b>	<b>2-3 days</b>	<b>4-5 days</b>	<b>6-7 days</b>
How many days did you exercise or play so hard that your body got tired? <small>pac_m_009r1</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did you exercise really hard for 10 minutes or more? <small>pac_m_105r1</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did you exercise so much that you breathed hard? <small>pac_m_002e1</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days were you so physically active that you sweated? <small>pac_m_008r1</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 12***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Almost always</b>	<b>Always</b>
I had difficulty falling asleep <small>sq005c</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I slept through the night <small>sq020c_r</small>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I had a problem with my sleep <small>sq041c_r</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I had trouble sleeping <small>sq042c</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 13***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section***Please respond to each question or statement by marking one box per row.**

<b>In the past 4 weeks...</b>	<b>Never</b>	<b>Rarely</b>	<b>Some-times</b>	<b>Often</b>	<b>Always</b>
I felt I had a strong relationship with my family <small>fam_fb_0_74r1r</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt really important to my family <small>fam_fb_0_88r1r</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I got all the help I needed from my family <small>fam_fb_0_29r1r</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My family and I had fun together <small>fam_fi_12_0r1r</small>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 14***Interviewer instructions: Write in 88 for refused for this section***NEXT ARE SOME QUESTIONS ABOUT WAYS PEOPLE SOMETIMES CHANGE AFTER DIFFICULT EVENTS.****For each of the next statements indicate the degree to which this change happened in your life as a result of your burn injury.**

	No change	A little	Some	A lot	Don't know
I learned how nice and helpful some people can be. <b>ptgic_1</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I can now handle big problems better than I used to. <b>ptgic_2</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I know what is important to me better than I used to. <b>ptgic_3</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I understand how God works better than I used to. <b>ptgic_4</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel closer to other people (friends or family) than I used to. <b>ptgic_5</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I appreciate (enjoy) each day more than I used to. <b>ptgic_6</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I now have a chance to do some things I couldn't do before. <b>ptgic_7</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
My faith (belief) in God is stronger than it was before. <b>ptgic_8</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I have learned that I can deal with more things than I thought I could before. <b>ptgic_9</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I have new ideas about how I want things to be when I grow up. <b>ptgic_10</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

**Section 15**

"This is the last section of the survey"

1. What is your current weight? (lbs) **wtfu** \_\_\_\_\_  I don't know 2. What is your current height? (feet/inches) **htfu** \_\_\_\_\_  I don't know

<p><b>3. Where are you currently living? (Choose only one) <span style="color: red;">resdenclu</span></b></p> <p><input type="checkbox"/> 1. Private residence</p> <p><input type="checkbox"/> 2. Nursing home</p> <p><input type="checkbox"/> 4. Correctional institution</p> <p><input type="checkbox"/> 5. Hotel/motel</p> <p><input type="checkbox"/> 6. Homeless</p> <p><input type="checkbox"/> 7. Hospital</p>	<div style="border: 1px solid black; width: 50px; height: 20px; margin: 0 auto; text-align: center;">88/Refused</div> <div style="border: 1px solid black; width: 50px; height: 20px; margin: 0 auto; text-align: center;">99/Unknown</div>
<p><b>4. What is your current zip code? <span style="color: red;">zipfu</span> _____</b></p> <p><input type="checkbox"/> 1 Not applicable (not living in U.S.) <small>(code 99999 for unknown)</small></p> <p><input type="checkbox"/> 2 Not applicable (homeless) <small>Checkboxes correspond to variable "zipfupmiss"</small></p>	
<p><b>5. Who are you currently living with? (Choose all that apply)</b></p> <p><input type="checkbox"/> 4. Parent or step-parent <span style="color: red;">livingafu__4</span></p> <p><input type="checkbox"/> 5. Other relative (siblings, grandparents) <span style="color: red;">livingafu__5</span></p> <p><input type="checkbox"/> 6. Others, not part of family <span style="color: red;">livingafu__6</span></p> <p><input type="checkbox"/> 7. Guardian <span style="color: red;">livingafu__7</span></p>	<div style="border: 1px solid black; width: 50px; height: 20px; margin: 0 auto; text-align: center;">88/Refused</div> <div style="border: 1px solid black; width: 50px; height: 20px; margin: 0 auto; text-align: center;">99/Unknown</div> <p style="font-size: small; color: blue;"><u>Variable notes:</u> For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)</p>
<p><b>6. What is your current school status? <span style="color: red;">aschoolfu</span></b></p> <p><input type="checkbox"/> 1. In school</p> <p><input type="checkbox"/> 2. Not in school <span style="font-size: 2em; color: black;">➔</span></p>	<p><i>If you aren't going to school, why not?</i></p> <p><input type="checkbox"/> 1 Burn related</p> <p><input type="checkbox"/> 2 Other medical problems</p> <p><input type="checkbox"/> 4 Emotional/social reasons</p> <p><input type="checkbox"/> 5 Legal reasons/jail</p> <p><input type="checkbox"/> 6 Substance abuse</p> <p><input type="checkbox"/> 7 Personal choice</p> <p><input type="checkbox"/> 8 Other</p> <p><input type="checkbox"/> 77 Not applicable (going to school)</p> <p><input type="checkbox"/> 99 I don't know</p>
<p><b>7. If the participant hadn't already returned to school before their last research study questionnaire, but they are in school now, <span style="color: red;">retrndat</span></b></p> <p>What was your first date to return to school since your injury? (Please take your best guess if you don't know the exact date): ____/____/____</p>	
<p><b>8. How many years of education have you completed? (If you have not graduated from high school, please indicate the number of years spent in school). <span style="color: red;">educfup</span></b></p> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 5. 5 years</p> <p><input type="checkbox"/> 6. 6 years</p> <p><input type="checkbox"/> 7. 7 years</p> <p><input type="checkbox"/> 8. 8 years</p> <p><input type="checkbox"/> 9. 9 years</p> <p><input type="checkbox"/> 10. 10 years</p> <p><input type="checkbox"/> 11. 11 or 12 years; no diploma</p> <p><input type="checkbox"/> 12. High school diploma or equivalent (ie, GED)</p> <p><input type="checkbox"/> 66. Other</p>	

<p>9. Are you currently receiving <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)</p> <div style="display: flex; align-items: flex-start;"> <div style="margin-right: 10px;"> <p>disincfup__3</p> <p>disincfup__5</p> <p>disincfup__6</p> </div> <div style="flex-grow: 1;"> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. I am not receiving disability income disincfup__1</li> <li><input type="checkbox"/> 2. Social Security Disability disincfup__2</li> <li><input type="checkbox"/> 3. Private long term insurance disability income</li> <li><input type="checkbox"/> 4. Supplemental security income (SSI) disincfup__4</li> <li><input type="checkbox"/> 5. Worker's compensation</li> <li><input type="checkbox"/> 6. Other (please specify) disincfupo (text field)</li> <li><input type="checkbox"/> 99. I don't know disincfup__99</li> </ul> </div> <div style="margin-left: 10px; border: 1px solid black; padding: 2px;"> <p>88/Refused</p> <p>99/Unknown</p> </div> </div> <p style="color: red; margin-top: 10px;"><b>Variable notes:</b> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked).</p>	<p><i>If yes, are you receiving disability income due to your burn injury? disincbrn</i></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. Yes, I am receiving disability income due to my burn injury</li> <li><input type="checkbox"/> 2. No, I am not receiving disability income due to my burn injury</li> <li><input type="checkbox"/> 77. Not applicable (not receiving disability income)</li> <li><input type="checkbox"/> 99. I don't know</li> </ul> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;"> <p>88/Refused</p> </div>
<p>10. Do you currently have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? physprobfup</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. Yes</li> <li><input type="checkbox"/> 2. No</li> <li><input type="checkbox"/> 99. I don't know</li> </ul> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;"> <p>88/Refused</p> </div>	

Length of interview: \_\_\_\_\_

“Is there anything else you would like to tell us? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you very much for sharing your experiences with us.”

## BMS Pediatric Self Report 8-12 Interview Form II: Research Staff Instructions

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

<b>Form II Administration:</b>			
<p><b>Follow-up period</b> <i>follow_up</i></p> <p><input type="checkbox"/> 1. 6-month follow-up</p> <p><input type="checkbox"/> 2. 12 month follow-up</p> <p><input type="checkbox"/> 3. 24 month follow-up</p> <p><input type="checkbox"/> 4. 5 year follow-up</p> <p><input type="checkbox"/> 5. 10 year follow-up</p>	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; padding: 5px; vertical-align: top;"> <p><b>What is the method of</b> <i>admin_fup</i> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p> </td> <td style="width: 50%; padding: 5px; vertical-align: top;"> <p><b>What is the language of</b> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. English <i>language_fup</i></p> <p><input type="checkbox"/> 2. Spanish</p> </td> </tr> </table>	<p><b>What is the method of</b> <i>admin_fup</i> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>	<p><b>What is the language of</b> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. English <i>language_fup</i></p> <p><input type="checkbox"/> 2. Spanish</p>
<p><b>What is the method of</b> <i>admin_fup</i> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>	<p><b>What is the language of</b> <b>administration of this form?</b></p> <p><input type="checkbox"/> 1. English <i>language_fup</i></p> <p><input type="checkbox"/> 2. Spanish</p>		
<p><b>What is the status of this follow-up assessment?</b></p> <p><input type="checkbox"/> 1. Some or all assessment done <i>lostfolo</i></p> <p><input type="checkbox"/> 2. Death due to burn related complications (update date and cause of death on Patient Status Form)</p> <p><input type="checkbox"/> 3. Death due to non- burn related complications (update date and cause of death on Patient Status Form)</p> <p><input type="checkbox"/> 4. Unable to locate</p> <p><input type="checkbox"/> 5. Refused this assessment</p> <p><input type="checkbox"/> 6. Unable to test/med comp/incapable of responding</p> <p><input type="checkbox"/> 7. Failed to respond</p> <p><input type="checkbox"/> 8. Did not consent to future assessment/withdrew</p> <p><input type="checkbox"/> 11. Incarcerated</p> <p><input type="checkbox"/> 13. Still in hospital (not discharged yet)</p> <p><input type="checkbox"/> 14. Unable to travel for assessment</p> <p><input type="checkbox"/> 15. Death (unknown causes) (update date and cause of death on Patient Status Form)</p>	<p><b>If follow-up status is "unable to locate," mark the best reason, below:</b> <i>unabletolocate</i></p> <p><input type="checkbox"/> 1. Homeless at previous data collection</p> <p><input type="checkbox"/> 2. International place of residence</p> <p><input type="checkbox"/> 3. Participant is child who was/is in CPS custody or foster care and no contact information is available</p> <p><input type="checkbox"/> 4. No known current contact info</p> <p><input type="checkbox"/> 5. Other reasons</p> <p><input type="checkbox"/> 6. Unable to contact due to Shriners Hospital regulations</p>		

## Burn Model System Follow-up Survey: Introduction

**Introduction Script** (replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

“Hi my name is \_\_\_\_ and I am calling from \_\_\_\_\_ to ask you some questions about how you have been doing (since your injury)... or (since we last spoke with you on (last follow-up date)). Thank you for continuing to participate in our study. The aim of the study is to learn about how young people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I’ll be asking questions about your burn injury, your health, and other questions about you and people around you. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.” Please let me know at any time if you have any questions.”

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ fup\_date

As a reminder, your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.

“We’re going to go ahead and get started.”

### Section I

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

**The following questions ask about your appearance:**

	<b>Definitely true = 1</b>	<b>Mostly true = 2</b>	<b>Not sure = 3</b>	<b>Mostly false = 4</b>	<b>Definitely false = 5</b>
1. I feel that the burn is unattractive to others. <span style="color: red;">bodyim_1</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I think people would not want to touch me. <span style="color: red;">bodyim_2</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel unsure of myself among strangers. <span style="color: red;">bodyim_3</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Changes in my appearance have interfered with my relationships. <span style="color: red;">bodyim_4</span>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 2**

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

**This is a list of problems that kids sometimes have after experiencing an upsetting event. Read each one carefully and then choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.**

	<b>Not at all or only at one time=0</b>	<b>Once a week or less/ once in a while=1</b>	<b>2 to 4 times a week/ half the time=2</b>	<b>5 or more times a week/ almost always=3</b>
1. Having upsetting thoughts or images about your burn injury that came into your head when you didn't want them to <b>cpss_1</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Having bad dreams or nightmares <b>cpss_2</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Acting or feeling as if your burn injury was happening again (hearing something or seeing a picture about it and feeling as if I am there again) <b>cpss_3</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc) <b>cpss_4</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Having feelings in your body when you think about or hear about your burn injury (for example, breaking out into a sweat, heart beating fast) <b>cpss_5</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Trying not to think about, talk about, or have feelings about your burn injury <b>cpss_6</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Trying to avoid activities, people, or places that remind you of your burn injury <b>cpss_7</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Not being able to remember an important part of your burn injury <b>cpss_8</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Having much less interest or doing things you used to do <b>cpss_9</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Not feeling close to people around you <b>cpss_10</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) <b>cpss_11</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Feeling as if your future plans or hopes will not come true (for example, you will not have a job or getting married or having kids) <b>cpss_12</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Having trouble falling or staying asleep <b>cpss_13</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.	Not at all or only at one time	Once a week or less/ once in a while	2 to 4 times a week/ half the time	5 or more times a week/ almost always
14. Feeling irritable or having fits of anger <sup>cpss_14</sup>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Having trouble concentrating (for <sup>cpss_15</sup> example, losing track of a story on television, forgetting what you read, not paying attention in class)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Being overly careful (for example, checking to see who is around you and what is around you) <sup>cpss_16</sup>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Being jumpy or easily startled (for <sup>cpss_17</sup> example, when someone walks up behind you)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 3**

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

**Please respond to each item by marking one box per row.**

In the past 7 days...	Never	Almost Never	Some-times	Often	Almost always
1. I felt mad <sup>pr206r1</sup>	<input type="checkbox"/>				
2. I felt upset <sup>pr714r1</sup>	<input type="checkbox"/>				
3. I felt fed up <sup>pr5045r1</sup>	<input type="checkbox"/>				
4. I was so angry I felt like throwing something <sup>pr2319ar1</sup>	<input type="checkbox"/>				
5. I was so angry I felt like yelling at somebody <sup>pr2581r1</sup>	<input type="checkbox"/>				

**Section 4***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>Physical Function In the past 7 days...</b>	<b>With no trouble</b>	<b>With a little trouble</b>	<b>With some trouble</b>	<b>With a lot of trouble</b>	<b>Not able to do</b>
I could do sports and exercise that other kids my age could do pr235r1r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I could get up from the floor pr4124r1r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I could walk up stairs without holding on to anything pr2707r2r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I have been physically able to do the activities I enjoy most pr5023r1r	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
<b>Anxiety In the past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost always</b>
I felt like something awful might happen pr2220r2r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt nervous pr713r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt worried pr5044r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I worried when I was at home pr3459br1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Depressive symptoms In the past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost always</b>
I felt everything in my life went wrong pr5041r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt lonely pr711r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt sad pr228r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to have fun pr3952ar2r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Fatigue</b> In the past 7 days...	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost always</b>
Being tired made it hard for me to keep up with my schoolwork <b>pr4239ar2r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I got tired easily <b>pr2876r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I was too tired to do sports or exercise <b>pr4241r2r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I was too tired to enjoy the things I like to do <b>pr4196r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Peer relationships</b> In the past 7 days...					
I felt accepted by other kids my age <b>pr5018r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I was able to count on my friends <b>pr5058r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My friends and I helped each other out <b>pr5055r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Other kids wanted to be my friend <b>pr233r2r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Pain Interference</b> In the past 7 days...					
I had trouble sleeping when I had pain <b>pr3793r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to pay attention when I had pain <b>pr9004r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to run when I had pain <b>pr2045r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for me to walk one block when I had pain <b>pr2049r1r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Pain Intensity</b> In the past 7 days...												
How bad was your pain on average?...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>									
	0	1	2	3	4	5	6	7	8	9	10	
<b>88/Refused</b> <b>99/Unknown</b>	<b>No pain</b>								<b>Worst pain you can think of</b>			

<b>Section 5</b>					
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Indicate how much you agree or disagree:</b>					
	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1. My life is going well. pa066	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My life is just right. pa067	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I have a good life. pa070	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I have what I want in life. pa071	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Section 6</b>						
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>						
<b>Please respond to each question or statement by marking one box per row.</b>						
<b>In the past 7 days ...</b>		<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
I had trouble sleeping when I was itching bmsitch_1		<input checked="" type="checkbox"/> 0	<input checked="" type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input checked="" type="checkbox"/> 3	<input checked="" type="checkbox"/> 4
I felt angry when I was itching bmsitch_2		<input type="checkbox"/>				
It was hard for me to pay attention when I was itching bmsitch_4		<input type="checkbox"/>				
It was hard for me to have fun when I was itching bmsitch_5		<input type="checkbox"/>				
	<b>77=N/A</b> (I don't do schoolwork)	<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
I had trouble doing schoolwork when I was itching bmsitch_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*BMS Itch Interference Self Report Total Score: bmsitchscore\_ped*

<b>Section 7</b>					
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Please respond to each question or statement by marking one box per row.</b>					
<b>In the past 7 days...</b>	<b>No days</b>	<b>1 day</b>	<b>2-3 days</b>	<b>4-5 days</b>	<b>6-7 days</b>
How many days did you exercise or play so hard that your body got tired? pac_m_009r1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did you exercise really hard for 10 minutes or more? pac_m_105r1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did you exercise so much that you breathed hard? pac_m_002e1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days were you so physically active that you sweated? pac_m_008r1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 8***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Some- times</b>	<b>Almost always</b>	<b>Always</b>
I had difficulty falling asleep sq005c	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I slept through the night sq020c_r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I had a problem with my sleep sq041c_r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I had trouble sleeping sq042c	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 9***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 4 weeks...</b>	<b>Never</b>	<b>Rarely</b>	<b>Some- times</b>	<b>Often</b>	<b>Always</b>
I felt I had a strong relationship with my family fam_fb_0_74r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I felt really important to my family fam_fb_0_88r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I got all the help I needed from my family fam_fb_0_29r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My family and I had fun together fam_fi_12_0r1r	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 10**

*Interviewer instructions: Write in 88 for refused for this section.*

**“NEXT ARE SOME QUESTIONS ABOUT WAYS PEOPLE SOMETIMES CHANGE AFTER DIFFICULT EVENTS.**

**For each of the next statements indicate the degree to which this change happened in your life as a result of your burn injury.”**

“This is the last section of the survey.”

	<b>No change</b>	<b>A little</b>	<b>Some</b>	<b>A lot</b>	<b>Don't know</b>
I learned how nice and helpful some people can be. <i>ptgic_1</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I can now handle big problems better than I used to. <i>ptgic_2</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I know what is important to me better than I used to. <i>ptgic_3</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I understand how God works better than I used to. <i>ptgic_4</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel closer to other people (friends or family) than I used to. <i>ptgic_5</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I appreciate (enjoy) each day more than I used to. <i>ptgic_6</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I now have a chance to do some things I couldn't do before. <i>ptgic_7</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
My faith (belief) in God is stronger than it was before. <i>ptgic_8</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I have learned that I can deal with more things than I thought I could before. <i>ptgic_9</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I have new ideas about how I want things to be when I grow up. <i>ptgic_10</i>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Length of interview: \_\_\_\_\_

“Is there anything else you would like to tell us? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you very much for sharing with us!”

## **BMS Pediatric Proxy 8-17 Interview Form I: Research Staff Instructions**

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

<b>Form I Administration:</b>	
<p><b>Who is responding to this questionnaire? (Select all that apply)</b></p> <p><input type="checkbox"/> 1. Mother or stepmother proxydis__1</p> <p><input type="checkbox"/> 2. Father or stepfather proxydis__2</p> <p><input type="checkbox"/> 3. Guardian proxydis__3</p> <p><input type="checkbox"/> 4. Other proxydis__4</p>	<p><b>What is the method of administration of this form? admin</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>
<p><b>What is the language of administration of this form? language</b></p> <p><input type="checkbox"/> 1. English</p> <p><input type="checkbox"/> 2. Spanish</p>	<p><b>Checklist of forms: Mark when each is complete status</b></p> <p><input type="checkbox"/> 1. Patient Status Form</p> <p><input type="checkbox"/> 2. Medical Record Abstraction Form</p> <p><input type="checkbox"/> 3. Form I</p>

**Introduction script** (Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

"Thank you for agreeing to participate in this study. The aim of the study is to learn about how young people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I'll be asking questions about your child's burn injury, his/her health, and other questions about him/her and people around him/her. Some questions ask about what things were like before your child's burn injury, other questions are about his/her health now. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip." Please let me know at any time if you have any questions."

## Burn Model System Hospital Discharge Survey

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ disintdate

“We’re going to go ahead and get started.”

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section I</b>										
<i>Instructions: Please answer each question with a “yes” or “no”.</i> <i>If you answer “yes”, then please indicate to what extent this problem affects your child’s daily activities using these responses:</i>										
1 Not at all	2 To a very small extent	3 To a small extent	4 To a moderate extent	5 To a fairly great extent	6 To a great extent	7 To a very great extent				
Does your child have problems... Problem?				1	2	3	4	5	6	7
1. Seeing? <span style="color: red;">chcprox1, chcprox1a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hearing? <span style="color: red;">chcprox2, chcprox2a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Learning and understanding? <span style="color: red;">chcprox3, chcprox3a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <span style="color: red;">chcprox4, chcprox4a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Controlling emotions or behavior? <span style="color: red;">chcprox5, chcprox5a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. with Seizures or epilepsy? <span style="color: red;">chcprox6, chcprox6a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <span style="color: red;">chcprox7, chcprox7a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. with Teeth and gums? <span style="color: red;">chcprox8, chcprox8a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. with Digestion (eg reflux, vomiting, or constipation)? <span style="color: red;">chcprox9, chcprox9a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. with Type 1 or Type 2 diabetes? <span style="color: red;">chcprox10, chcprox10a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. with Growth? <span style="color: red;">chcprox11, chcprox11a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Sleeping? <span style="color: red;">chcprox12, chcprox12a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. with Repeated infections? <span style="color: red;">chcprox13, chcprox13a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. with Breathing (eg asthma)? <span style="color: red;">chcprox14, chcprox14a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)? <span style="color: red;">chcprox15, chcprox15a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)? <span style="color: red;">chcprox16, chcprox16a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)? <span style="color: red;">chcprox17, chcprox17a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain? <span style="color: red;">chcprox18, chcprox18a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Does your child have any other health problems? <span style="color: red;">chcprox19</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem: <span style="color: red;">chcprox19ot (text field)</span>					

### Pre-Injury History Section

“The next section of questions is about your child’s situation before the injury. Your answers will help us understand problems related to the injury. Later in the survey there will be some similar questions about after the burn injury.”

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section 2</b>					
Indicate how much you agree or disagree:					
In the four weeks before my child’s burn injury...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. My child’s life was going well. <span style="color: red;">papxy066pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My child’s life was just right. <span style="color: red;">papxy067pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My child had a good life. <span style="color: red;">papxy070pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. My child had what he/she wanted in life. <span style="color: red;">papxy071pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

NIH Toolbox General Life Satisfaction Proxy T-Score Variable: tbgilstscoreprx\_pre

<b>Section 3</b>	
<p>1. Before your child’s burn injury, where was he/she living? (Choose only one) <span style="color: red;">resdencprx</span></p> <p><input type="checkbox"/> 1. Private residence</p> <p><input type="checkbox"/> 2. Nursing home</p> <p><input type="checkbox"/> 4. Correctional institution</p> <p><input type="checkbox"/> 5. Hotel/motel</p> <p><input type="checkbox"/> 6. Homeless</p> <p><input type="checkbox"/> 7. Hospital</p>	<p><span style="border: 1px solid black; padding: 2px;">88/Refused</span></p> <p><span style="border: 1px solid black; padding: 2px;">99/Unknown</span></p> <p><small><i>Variable Notes:</i> In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.</small></p>
<p>2. What was your child’s zip code at the time of his/her burn injury? <span style="color: red;">zipprx_pre</span></p> <p><input checked="" type="checkbox"/> 1 Not applicable (not living in U.S.) (code 99999 for unknown)</p> <p><input type="checkbox"/> 2 Not applicable (homeless)</p> <p style="color: red;"><i>Checkboxes correspond to variable "zippremisprx"</i></p>	
<p>3. Who was your child living with before his/her burn injury? (Choose all that apply)</p> <p><input type="checkbox"/> 4. Parent or step-parent <span style="color: red;">livingaprx__4</span></p> <p><input type="checkbox"/> 5. Other relative (siblings, grandparents) <span style="color: red;">livingaprx__5</span></p> <p><input type="checkbox"/> 6. Others, not part of family <span style="color: red;">livingaprx__6</span></p> <p><input type="checkbox"/> 7. Guardian <span style="color: red;">livingaprx__7</span></p>	<p><span style="border: 1px solid black; padding: 2px;">88/Refused</span></p> <p><span style="border: 1px solid black; padding: 2px;">99/Unknown</span></p> <p><small><i>Variable notes:</i> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked)</small></p> <p style="color: red;"><i>livingaprx__88</i></p> <p style="color: red;"><i>livingaprx__99</i></p>

<p>4. Was your child enrolled in school at the time of his/her burn injury? <span style="color: red;">schoolprx</span></p> <p><input type="checkbox"/> 1. Yes, in school</p> <p><input type="checkbox"/> 2. No, not in school</p>	<p><i>If your child was not enrolled in school at the time of his/her burn injury, why not?</i> <span style="color: red;">whynotprx</span></p> <p><input type="checkbox"/> 2. Medical problems</p> <p><input type="checkbox"/> 4. Emotional/social reasons</p> <p><input type="checkbox"/> 5. Legal reasons/jail</p> <p><input type="checkbox"/> 6. Substance abuse</p> <p><input type="checkbox"/> 7. Personal choice</p> <p><input type="checkbox"/> 8. Other</p> <p><input type="checkbox"/> 77. Not applicable (going to school)</p> <p><input type="checkbox"/> 99. I don't know</p>
	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; display: inline-block;">99/Unknown</div>
<p>5. Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group?</p> <p><input type="checkbox"/> 1. Above the grade level he/she should be for his/her age <span style="color: red;">gradelvlprx</span></p> <p><input type="checkbox"/> 2. At the grade level he/she should be for his/her age</p> <p><input type="checkbox"/> 3. Lower than the grade level he/she should be for his/her age</p> <p><input type="checkbox"/> 77. Not applicable</p> <p><input type="checkbox"/> 99. I don't know</p>	
<p>6. In school, has your child ever been classified as a special education student? <span style="color: red;">speducdisprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable</p> <p><input type="checkbox"/> 99. I don't know</p>	
<p>7. Before his/her burn injury, did your child have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? <span style="color: red;">physprobpreprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	
<p>8. Before his/her burn injury, was your child ever told by a doctor that he/she had any of the following psychological issues (choose all that apply)? <span style="color: red;">psychlistprx</span></p> <p><input type="checkbox"/> 0. None/no psychological issues</p> <p><input type="checkbox"/> 1. Depression</p> <p><input type="checkbox"/> 2. Bipolar disorder</p> <p><input type="checkbox"/> 3. Anxiety</p> <p><input type="checkbox"/> 4. Post-Traumatic Stress Disorder (PTSD)</p> <p><input type="checkbox"/> 5. Schizophrenia/psychotic disorder</p> <p><input type="checkbox"/> 6. Other, please explain: <span style="color: red;">psychlistotprx</span> (text field) _____</p> <p><input type="checkbox"/> 99. I don't know</p>	

*Variable notes:*  
 There are two other variables in the database, psychlistprx2 and psychlistprx3, with the same coding in case more than one or two issues were selected.

<b>Section 4</b>	
<p>1. In <b>the month before</b> your child's burn injury did he/she take <u>prescription</u> medication for pain on a regular basis? <span style="color: red;">pmedprx_pre</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>

In the past 12 months...	
2. In the past 12 months, did your child take medication for being worried, tense, or anxious?	
<input type="checkbox"/> 1. Yes <b>wmedprx_pre</b>	88/Refused
<input type="checkbox"/> 2. No	
<input type="checkbox"/> 99. I don't know	
3. In the past 12 months, did your child take medication for being sad, empty, or depressed?	
<input type="checkbox"/> 1. Yes	88/Refused
<input type="checkbox"/> 2. No	
<input type="checkbox"/> 99. I don't know <b>smedprx_pre</b>	
4. Did your child receive psychological therapy or counseling in the last 12 months?	
<input type="checkbox"/> 1. Yes <b>psychtrprx</b>	88/Refused
<input type="checkbox"/> 2. No	
<input type="checkbox"/> 99. I don't know	

### Post-Injury History Section

“All the questions you just answered were about your child and the time before your child’s burn injury. Next I have some questions about your child and his/her situation after his/her burn injury.”

Section 5	
1. Is your child of Hispanic, Latino, or Spanish Origin? <b>ethnicity</b>	99/Unknown
<input type="checkbox"/> 1. Yes, Hispanic, Latino, or Spanish origin	
<input type="checkbox"/> 2. No, not of Hispanic, Latino, or Spanish origin	
<input type="checkbox"/> 88. Prefer not to answer	
2. What is your child’s race? <b>race</b>	99/Unknown
<input type="checkbox"/> 1. African-American or Black	
<input type="checkbox"/> 2. Asian	
<input type="checkbox"/> 3. White	
<input type="checkbox"/> 4. American Indian/Alaskan Native	
<input type="checkbox"/> 5. Native Hawaiian or Other Pacific Islander	
<input type="checkbox"/> 6. More than one race ((please specify): <b>racemto (text field)</b>	
<input type="checkbox"/> 7. Some other race (please specify): <b>raceotr (text field)</b>	
<input type="checkbox"/> 88. Prefer not to answer	

<b>Section 6</b>		
<p><b>1. After your child's hospital discharge, where is/will he/she be living? (Choose only one)</b></p> <p><input type="checkbox"/> 1. Private residence <b>dislivsitprx</b></p> <p><input type="checkbox"/> 2. Nursing home</p> <p><input type="checkbox"/> 4. Correctional institution</p> <p><input type="checkbox"/> 5. Hotel/motel</p> <p><input type="checkbox"/> 6. Homeless</p> <p><input type="checkbox"/> 7. Hospital</p>	<p><b>Variable notes:</b> In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobilehome) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p><b>2. Who will your child be living with after hospital discharge? (Choose all that apply)</b></p> <p><input type="checkbox"/> 4. Parent or step-parent <b>livhsdisprx__4</b></p> <p><input type="checkbox"/> 5. Other relative (siblings, grandparents) <b>livhsdisprx__5</b></p> <p><input type="checkbox"/> 6. Others, not part of family <b>livhsdisprx__6</b></p> <p><input type="checkbox"/> 7. Guardian <b>livhsdisprx__7</b></p>	<p><b>Variable notes:</b> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked)</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p><b>3. How many years of education has your child completed? <b>educdisprx</b></b></p> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 5. 5 years</p> <p><input type="checkbox"/> 6. 6 years</p> <p><input type="checkbox"/> 7. 7 years</p> <p><input type="checkbox"/> 8. 8 years</p> <p><input type="checkbox"/> 9. 9 years</p> <p><input type="checkbox"/> 10. 10 years</p> <p><input type="checkbox"/> 11. 11 or 12 years; no diploma</p> <p><input type="checkbox"/> 12. High school diploma or equivalent (ie, GED)</p> <p><input type="checkbox"/> 66. Other</p>		<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<p>“The following question asks about your income. We appreciate this information because income is often related to health. For instance, we'd like to know if families with lower reported income have more trouble accessing health care, such as dental care or physical therapy. Having this information helps us advocate for better programs that serve people with burn injuries.”</p>		
<p><b>4. Approximately what was your family's total income in the last full year before your burn injury (total income of all family members living with you in your household)? (in U.S. dollars)</b></p> <p><input type="checkbox"/> 1. Less than \$25,000 <b>hinccatpreprx</b></p> <p><input type="checkbox"/> 2. \$25,000-\$49,999</p> <p><input type="checkbox"/> 3. \$50,000-\$99,999</p> <p><input type="checkbox"/> 4. \$100,000-\$149,999</p> <p><input type="checkbox"/> 5. \$150,000-\$199,999</p> <p><input type="checkbox"/> 6. \$200,000 or more</p> <p><input type="checkbox"/> 7. Living outside the United States</p> <p><input type="checkbox"/> 77. Not applicable (e.g., living in an institution)</p> <p><input type="checkbox"/> 88. Prefer not to answer</p>		<div style="border: 1px solid black; padding: 2px;">99/Unknown</div>

5. How many people are in your household? \_\_\_\_\_ numhspreprx

88/Refused  
99/Unknown

6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)

1. My child is not receiving disability income disincdisprx\_\_1

2. Social Security Disability disincdisprx\_\_2

3. Private long term insurance disability income disincdisprx\_\_3

4. Supplemental security income (SSI) disincdisprx\_\_4

5. Worker's compensation disincdisprx\_\_5

6. Other (please specify) disincdisprx\_\_6 disincdisopr (text field)

99. I don't know disincdisprx\_\_99

88/Refused  
disincdisprx\_\_88

*Variable notes:*  
For each variable, 0 = "no"(not checked) and 1 = "yes" (checked)

*Interviewer Instructions: If the child is **under 14 years old**, you are **finished** with the survey after asking the last question in this section below.*

*If the child is **between 14 and 17 years old**, please complete **Section 7** on the last page.*

Length of interview: \_\_\_\_\_

If the child is under 14 years old, say, "Is there anything else you would like to tell us?"

---

"We'll be contacting you in about 6 months to see how your child is doing. Thank you very much for sharing your experiences with us!"

**Section 7**

**During the 4 weeks before your child's burn:**

1. Did your child take personal responsibility for grooming when asked? cip2prx\_pre

1. Often

2. Sometimes

3. Never

88/Refused  
99/Unknown

**Approximately how many times during the 4 weeks before the burn did your child participate in the following activities outside of his/her home?**

2. Shopping ci3prx\_pre

1. Never

2. 1-4 times

3. 5 or more times

88/Refused  
99/Unknown

3. Leisure activities such as movies, sports, and restaurants. ci4prx\_pre

1. Never

2. 1-4 times

3. 5 or more times

88/Refused  
99/Unknown

4. Visiting friends or relatives ci5prx\_pre

1. Never

2. 1-4 times

3. 5 or more times

88/Refused  
99/Unknown

<b>During the 4 weeks before your child's burn:</b>			
<p>5. When your child participated in leisure activities did he/she usually do this alone or with others?</p> <p><input type="checkbox"/> 1. Mostly alone <span style="color: red;">cip6prx_pre</span></p> <p><input type="checkbox"/> 3. Mostly with family members</p> <p><input type="checkbox"/> 4. Mostly with friends</p> <p><input type="checkbox"/> 5. With a combination of family and friends</p> <p><input type="checkbox"/> 77. Not applicable (no leisure activities)</p>	<table border="1"> <tr><td>88/Refused</td></tr> <tr><td>99/Unknown</td></tr> </table>	88/Refused	99/Unknown
88/Refused			
99/Unknown			
<p>6. Did your child have a best friend with whom he/she confided? <span style="color: red;">cip7prx_pre</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No <span style="color: red;"><i>CIQ Social Integration Subscale Proxy Total Score Variable: ciqsicprx_pre</i></span></p>	<table border="1"> <tr><td>88/Refused</td></tr> <tr><td>99/Unknown</td></tr> </table>	88/Refused	99/Unknown
88/Refused			
99/Unknown			
<p>Length of interview: _____</p> <p>"Is there anything else you would like to tell us?"</p> <p>_____</p> <p>_____</p>			
<p>"We'll be contacting you in about 6 months to see how your child is doing. Thank you very much for sharing your experiences with us!"</p>			

**BMS Pediatric Proxy 8-17 Interview Form II:  
Research Staff Instructions**

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead. Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

<b>Form II Administration:</b>	
<b>Who is responding to this questionnaire?</b> <b>(Select all that apply)</b> <input type="checkbox"/> 1. Mother or stepmother <b>proxy__1</b> <input type="checkbox"/> 2. Father or stepfather <b>proxy__2</b> <input type="checkbox"/> 3. Guardian <b>proxy__3</b> <input type="checkbox"/> 4. Other <b>proxy__4</b>	<b>Follow-up period</b> <b>follow_up</b> <input type="checkbox"/> 1. 6-month follow-up <input type="checkbox"/> 2. 12 month follow-up <input type="checkbox"/> 3. 24 month follow-up <input type="checkbox"/> 4. 5 year follow-up <input type="checkbox"/> 5. 10 year follow-up <input type="checkbox"/> 6. 15 year follow-up
<b>What is the method of administration of this form?</b> <b>admin_fup</b> <input type="checkbox"/> 1. In person interview <input type="checkbox"/> 3. Telephone interview <input type="checkbox"/> 5. Medical Record Review	<b>What is the language of administration of this form?</b> <input type="checkbox"/> 1. English <b>language_fup</b> <input type="checkbox"/> 2. Spanish
<b>What is the status of this follow-up assessment?</b> <b>lostfo</b> <input type="checkbox"/> 1. Some or all assessment done <input type="checkbox"/> 2. Death due to burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 3. Death due to non- burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 4. Unable to locate <input type="checkbox"/> 5. Refused this assessment <input type="checkbox"/> 6. Unable to test/med comp/incapable of responding <input type="checkbox"/> 7. Failed to respond <input type="checkbox"/> 8. Did not consent to future assessment/withdrew <input type="checkbox"/> 11. Incarcerated <input type="checkbox"/> 13. Still in hospital (not discharged yet) <input type="checkbox"/> 14. Unable to travel for assessment <input type="checkbox"/> 15. Death (unknown causes) (update date and cause of death on Patient Status Form)	<b>If follow-up status is "unable to locate," mark the best reason, below:</b> <b>unabletolocate</b> <input type="checkbox"/> 1. Homeless at previous data collection <input type="checkbox"/> 2. International place of residence <input type="checkbox"/> 3. Participant is child who was/is in CPS custody or foster care and no contact information is available <input type="checkbox"/> 4. No known current contact info <input type="checkbox"/> 5. Other reasons <input type="checkbox"/> 6. Unable to contact due to Shriners Hospital regulations

## Burn Model System Follow-up Survey: Introduction

**Introduction Script** (replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

“Hi my name is \_\_\_\_ and I am calling from \_\_\_\_\_ to ask you some questions about how your child has been doing (since your injury)... or (since we last spoke with you on (last follow-up date)).

Thank you for continuing to participate in our study. The aim of the study is to learn about how young people do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I’ll be asking questions about your child’s burn injury, his/her health, and other questions about your child and people around him/her. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.” Please let me know at any time if you have any questions.”

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ fup\_date

“As a reminder, your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.”

“We’re going to go ahead and get started.”

### Section I

1. Since your last research study questionnaire, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? peersupprx

1. Yes  
 2. No  
 99. I don't know

88/Refused

<p>2. To your knowledge, in the last year has your child had COVID-19? <b>covidstatprx</b></p> <p>Or, since your last research study questionnaire if your child's burn was less than a year ago, has your child had COVID-19?</p> <p><input type="checkbox"/> 1. Yes </p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	<p>(If yes), What month and year did your child have COVID-19? (if your child has had COVID-19 more than once, provide the month and year of his/her <u>first</u> illness)</p> <p>Month: <b>covidmontprx</b></p> <p>Year: <b>covidyearprx</b></p> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused 99/Unknown</div> <p>What level of care did your child receive for COVID-19?</p> <p><input type="checkbox"/> 1. Did not seek medical care <b>covidcareprx</b></p> <p><input type="checkbox"/> 2. Received medical care but was not hospitalized</p> <p><input type="checkbox"/> 3. Was hospitalized</p> <p style="margin-left: 20px;">In the hospital... (if applicable) <b>covidventprx</b></p> <p style="margin-left: 40px;"><input type="checkbox"/> 1. He/she was NOT on a ventilator (breathing machine with tube down his/her throat)</p> <p style="margin-left: 40px;"><input type="checkbox"/> 2. He/she was on a ventilator</p> <p style="margin-left: 40px;"><input type="checkbox"/> 3. I don't know</p> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>
<p>3. Since your last research study questionnaire, has your child received any of the following services at home or outpatient? (Choose all that apply)</p> <p><input type="checkbox"/> 1. No services <b>servicesprx__1</b></p> <p><input type="checkbox"/> 2. Occupational therapy <b>servicesprx__2</b></p> <p><input type="checkbox"/> 3. Physical therapy <b>servicesprx__3</b></p> <p><input type="checkbox"/> 4. Speech language pathology <b>servicesprx__4</b></p> <p><input type="checkbox"/> 5. Social work <b>servicesprx__5</b></p> <p><input type="checkbox"/> 6. Psychological services <b>servicesprx__6</b></p> <p><input type="checkbox"/> 7. Vocational services or child life services <b>servicesprx__7</b></p> <p><input type="checkbox"/> 99. I don't know <b>servicesprx__99</b></p> <div style="border: 1px solid gray; padding: 5px; margin-top: 10px; width: fit-content;"> <p><i>If clarification is needed, say,</i>                      "Examples of occupational therapy include helping with adjusting to a school environment after injury. Examples of physical therapy include range of motion and walking exercises."</p> </div> <p><i>Variable note: For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)</i></p> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused <b>servicesprx__88</b></div>	
<p><b>Interviewer Instructions: If the participant didn't receive any services OR if you didn't receive PT/OT, skip to #8 on page 4</b></p>	
<p>4. If yes to OT and/or PT, How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? (If you don't know exactly, use your best guess) <b>numtherprx</b></p> <p><input type="checkbox"/> 1. One</p> <p><input type="checkbox"/> 2. 2 to 4</p> <p><input type="checkbox"/> 3. 5 to 10</p> <p><input type="checkbox"/> 4. More than 10</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)  skip to #8 on page 4</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	
<p>If yes to OT and/or PT, Since your last research study questionnaire, <u>where</u> did your child receive his/her outpatient occupational or physical burn therapy?</p>	
<p>5. At the burn center? <b>ther_brn_ctrprx</b></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="text-align: right; border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	

<p>6. At any other facility? <span style="color: red;">ther_otrprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
<p>7. Using telehealth? (for example, meeting with his/her therapist using video conferencing)</p> <p><input type="checkbox"/> 1. Yes <span style="color: red;">telehlthprx</span></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
<p>8. Since your last research study questionnaire, has your child had any burn related surgeries (such as surgeries for open wounds or scar management)?</p> <p><input type="checkbox"/> 1. Yes <span style="font-size: 2em;">→</span></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> <p style="color: red; margin-top: 5px;">surgery_fuprx</p>	<p>(If your child <u>did</u> have burn related surgeries) Has your child had any burn-related surgeries outside of this clinical center? <span style="color: red;">surgoutprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>

**Section 2**

*"Please answer each question with a "yes" or "no". If you answer "yes", then please indicate to what extent this problem affects your child's daily activities using these responses:"*

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

		1	2	3	4	5	6	7
		To a very great extent						
		To a great extent						
		To a fairly great extent						
		To a moderate extent						
		To a small extent						
		To a very small extent						
		Not at all						
Does your child have problems...	Problem?	1	2	3	4	5	6	7
1. Seeing? <span style="color: red;">chcprox1, chcprox1a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
2. Hearing? <span style="color: red;">chcprox2, chcprox2a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
3. Learning and understanding? <span style="color: red;">chcprox3, chcprox3a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <span style="color: red;">chcprox4, chcprox4a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
5. Controlling emotions or behavior? <span style="color: red;">chcprox5, chcprox5a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
6. with Seizures or epilepsy? <span style="color: red;">chcprox6, chcprox6a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <span style="color: red;">chcprox7, chcprox7a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
8. with Teeth and gums? <span style="color: red;">chcprox8, chcprox8a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
9. with Digestion (eg reflux, vomiting, or constipation)? <span style="color: red;">chcprox9, chcprox9a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
10. with Type 1 or Type 2 diabetes? <span style="color: red;">chcprox10, chcprox10a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
11. with Growth? <span style="color: red;">chcprox11, chcprox11a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						
12. Sleeping? <span style="color: red;">chcprox12, chcprox12a</span>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>						

Does your child have problems...	Problem?	1	2	3	4	5	6	7
13. with Repeated infections? <b>chcprox13, chcprox13a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. with Breathing (eg asthma)? <b>chcprox14, chcprox14a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)? <b>chcprox15, chcprox15a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)? <b>chcprox16, chcprox16a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)? <b>chcprox17, chcprox17a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain? <b>chcprox18, chcprox18a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Does your child have any other health problems? <b>chcprox19</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem: <b>chcprox19ot (text field)</b>						

Section 3	
1. Is your child <b>currently</b> taking <u>prescription</u> medication for pain on a regular basis? <input type="checkbox"/> 1. Yes <b>pmedprx_curr</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	88/Refused
2. Is your child <b>currently</b> taking <u>prescription</u> medication for itch on a regular basis? <input type="checkbox"/> 1. Yes <b>imedprx</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	88/Refused
3. In the <b>past 12 months</b> , did your child take medication for being, worried, tense, or anxious? <input type="checkbox"/> 1. Yes <b>wmedprx</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	88/Refused
4. In the <b>past 12 months</b> , did your child take medication for being sad, empty, or depressed? <input type="checkbox"/> 1. Yes <b>smedprx</b> <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	88/Refused
5. Since your last research study questionnaire, has your child received psychological therapy or counseling due to his/her burn injury? <b>psychtherprx</b> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	88/Refused

**Section 4***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***The following questions ask about this child's appearance:**

	<b>Definitely true = 1</b>	<b>Mostly true = 2</b>	<b>Not sure = 3</b>	<b>Mostly false = 4</b>	<b>Definitely false = 5</b>
1. This child feels that the burn is unattractive to others. <i>bodyimp_1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This child thinks that people would not want to touch him/her. <i>bodyimp_2</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. This child feels unsure of himself/herself among strangers. <i>bodyimp_3</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Changes in this child's appearance have interfered with his/her relationships. <i>bodyimp_4</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Body Image Proxy Total Score Variable: bodyim\_tot\_proxy***Section 5***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child felt mad <i>pflanger1r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child was so angry he/she felt like yelling at somebody <i>pflanger5r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child was so angry he/she felt like throwing something <i>pflanger3r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt upset <i>pflanger10r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
When my child got mad, he/she stayed mad <i>pflanger8r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Anger Proxy T-score Variable: angtscore\_proxy***Section 6***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>Physical Function Mobility In the past 7 days...</b>	<b>With no trouble</b>	<b>With a little trouble</b>	<b>With some trouble</b>	<b>With a lot of trouble</b>	<b>Not able to do</b>
My child could do sports and exercise that other kids his/her age could do <i>pf1mobil3r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could get up from the floor <i>pf3mobil9r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could walk up stairs without holding on to anything <i>pf2mobil4r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child has been physically able to do the activities he/she enjoys most <i>pf1mobil1r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

*PROMIS Physical Function Mobility Proxy T-Score Variable: pfmobtscore\_proxy*

<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>						
<b>Anxiety</b> <b>In the past 7 days...</b>	<i>PROMIS Anxiety Proxy T-score Variable: anxtscore_proxy</i>	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
My child felt like something awful might happen	<i>pf2anxiety1r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt nervous	<i>pf1anxiety8r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt worried	<i>pf2anxiety9r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child worried when he/she was at home	<i>pf2anxiety5r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>						
<b>Depressive Symptoms</b> <b>In the past 7 days...</b>	<i>PROMIS Depressive Symptoms T-Score Variable: deptscore_proxy</i>	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
My child felt everything in his/her life went wrong	<i>pf1depr7r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt lonely	<i>pf2depr10r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt sad	<i>pf2depr3r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for my child to have fun	<i>pf2depr6r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>						
<b>Fatigue</b> <b>In past 7 days...</b>	<i>PROMIS Fatigue T-Score Variable: fattscore_proxy</i>	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
Being tired made it hard for my child to keep up with schoolwork	<i>pf2fatigue8r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child got tired easily	<i>pf4fatigue3r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child was too tired to do sports or exercise	<i>pf3fatigue8r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child was too tired to enjoy the things he/she likes to do	<i>pf4fatigue4r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>						
<b>Peer Relationships</b> <b>In the past 7 days...</b>		<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
My child felt accepted by other kids his/her age	<i>pf3socabil9r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child was able to count on his/her friends	<i>pf4socabil12r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child and his/her friends helped each other out	<i>pf2socrole4r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Other kids wanted to be my child's friend	<i>pf1socabil2r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Peer Relationships Proxy T-Score Variable: peertscore\_proxy*

<b>Pain Interference</b> In the past 7 days...	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
My child had trouble sleeping when he/she had pain <b>pf2pain5r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for my child to pay attention when he/she had pain <b>pf3pain2r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for my child to run when he/she had pain <b>pf2pain4r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
It was hard for my child to walk one block when he/she had pain <b>pf1pain4r</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Pain Interference Proxy T-Score Variable: painintscore\_proxy*

<b>Pain Intensity</b> In the past 7 days...											
How bad was your child's pain on average?...	<input type="checkbox"/>	<input type="checkbox"/>									
<b>prx9033r1</b>	0	1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/> 88/Refused	<b>No pain</b>									<b>Worst pain you can think of</b>	
<input type="checkbox"/> 99/Unknown											

<b>Section 7</b> <i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Please respond to each question or statement by marking one box per row.</b>					
<b>In the past 7 days...</b>	<b>With no trouble</b>	<b>With a little trouble</b>	<b>With some trouble</b>	<b>With a lot of trouble</b>	<b>Not able to do</b>
My child could button his/her shirt or pants <b>pf2uprext3r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could open a jar by himself/herself <b>pf4uprext1r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could open the rings in school binders <b>pf3uprext11r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could pour a drink from a full pitcher <b>pf4uprext10r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could pull a shirt on over his/her head without help <b>pf3uprext4r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could pull open heavy doors <b>pf3uprext9r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could put on his/her shoes without help <b>pf2uprext2r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child could use a key to unlock a door <b>pf3uprext7r</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

*PROMIS Upper Extremity Proxy T-Score Variable: pfuptscore\_proxy*

<b>Section 8</b>					
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
Indicate how much you agree or disagree:					
	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1. My child's life is going well. papxy066	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My child's life is just right. papxy067	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My child has a good life. papxy070	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. My child has what he/she wants in life. papxy071	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*NIH Toolbox Anger Proxy 8-17 T-Score Variable: tbangtscore\_proxy*

<b>Section 9</b>						
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>						
Please respond to each question or statement by marking one box per row.						
<b>In the past 7 days ...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>	
My child had trouble sleeping when he/she was itching bmsitchp_1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
My child felt angry when he/she was itching bmsitchp_2	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
It was hard for my child to pay attention when he/she was itching bmsitchp_4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
It was hard for my child to have fun when he/she was itching bmsitchp_5	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
	<b>N/A</b> (He/she doesn't do schoolwork)	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
My child had trouble doing schoolwork when he/she was itching bmsitchp_3	<input type="checkbox"/> 77	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

*BMS Itch Interference Proxy Report Total Score: bmsitchscore\_proxy*

**Section 10***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>No days</b>	<b>1 day</b>	<b>2-3 days</b>	<b>4-5 days</b>	<b>6-7 days</b>
How many days did your child exercise or play so hard that his/her body got tired? <i>pac_m_009_pxr1</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did your child exercise really hard for 10 minutes or more? <i>pac_m_105_pxr1</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did your child exercise so much that he/she breathed hard? <i>pac_m_002_pxr1</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days was your child so physically active that he/she sweated? <i>pac_m_008_pxr1</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Physical Activity Proxy T-score Variable: physactprxtscore***Section 11***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Almost Always</b>	<b>Always</b>
My child had difficulty falling asleep <i>sq005p</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child slept through the night <i>sq020p_r</i>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
My child had a problem with his/her sleep <i>sq041p_r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child had trouble sleeping <i>sq042p</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Sleep Disturbance Proxy T-score Variable: pedprxsleeptscore***Section 12***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 4 weeks...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
My child felt he/she had a strong relationship with our family <i>fam_fb_0_74_pxr1r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt he/she was really important to our family <i>fam_fb_0_88_pxr1r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt he/she got all the help he/she needed from our family <i>fam_fb_0_29_pxr1r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Our family and my child had fun together <i>fam_fi_1_20_pxr1r</i>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*PROMIS Family Relationships Proxy T-score Variable: prxfamrettscore*

<b>Section 13</b>	
1. What is your child's current weight? (lbs) <u>      </u> <small>wtfuprx</small> <input type="checkbox"/> I don't know	88/Refused
2. What is your child's current height? (feet/inches) <u>      </u> <small>htfuprx</small> <input type="checkbox"/> I don't know	88/Refused
3. Where is your child currently living? (Choose only one) <small>resdencfuprx</small> <input type="checkbox"/> 1. Private residence <input type="checkbox"/> 2. Nursing home <input type="checkbox"/> 4. Correctional institution <input type="checkbox"/> 5. Hotel/motel <input type="checkbox"/> 6. Homeless <input type="checkbox"/> 7. Hospital	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;">                     4. What is your child's current zip code? <small>zipfuprx</small>  <input type="checkbox"/> 1 Not applicable (not living in U.S.)  <small>(code 99999 for unknown)</small> </div> <div style="width: 45%;"> <input type="checkbox"/> 2 Not applicable (homeless)  <small>Checkboxes correspond to variable "zipfumissprx"</small> </div> </div>	
5. Who is your child currently living with? (Choose all that apply) <input type="checkbox"/> 4. Parent or step-parent <small>livingafuprx__4</small> <input type="checkbox"/> 5. Other relative (siblings, grandparents) <small>livingafuprx__5</small> <input type="checkbox"/> 6. Others, not part of family <small>livingafuprx__6</small> <input type="checkbox"/> 7. Guardian <small>livingafuprx__7</small>	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div> <p style="font-size: small; margin-top: 5px;"><i>Variable note:</i> For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)</p>
6. What is your child's current school status? <input type="checkbox"/> 1. In school <small>aschoolfuprx</small> <input type="checkbox"/> 2. Not in school	<div style="border: 1px solid black; padding: 5px;"> <p style="font-size: small; margin-top: 0;"><i>If your child isn't going to school, why not?</i> <small>whynotfuprx</small></p> <input type="checkbox"/> 1 Burn related  <input type="checkbox"/> 2 Other medical problems  <input type="checkbox"/> 4 Emotional/social reasons  <input type="checkbox"/> 5 Legal reasons/jail  <input type="checkbox"/> 6 Substance abuse  <input type="checkbox"/> 7 Personal choice  <input type="checkbox"/> 8 Other  <input type="checkbox"/> 77 Not applicable (going to school)  <input type="checkbox"/> 99 I don't know                     </div>
<div style="border: 1px solid black; padding: 5px;"> <p style="font-size: small; margin-top: 0;"><i>7. Interviewer instructions: If the child hadn't already returned to school before their last research study questionnaire, but the child is in school now, say:</i></p> <p>What was your child's first date to return to school since his/her injury? (Please take your best guess if you don't know the exact date): <u>   </u> / <u>   </u> / <u>   </u> <small>retrndat</small></p> </div>	

<p><b>8. How many years of education has your child completed?</b> <span style="color: red;">educfupprx</span></p> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 5. 5 years</p> <p><input type="checkbox"/> 6. 6 years</p> <p><input type="checkbox"/> 7. 7 years</p> <p><input type="checkbox"/> 8. 8 years</p> <p><input type="checkbox"/> 9. 9 years</p> <p><input type="checkbox"/> 10. 10 years</p> <p><input type="checkbox"/> 11. 11 or 12 years; no diploma</p> <p><input type="checkbox"/> 12. High school diploma or equivalent (ie, GED)</p> <p><input type="checkbox"/> 66. Other</p>	<div style="border: 1px solid black; padding: 2px; width: 50px; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: 50px; margin: 0 auto;">99/Unknown</div>
<p><b>9. Is your child currently receiving <u>disability</u> income such as Social Security Disability?</b> (Choose all that apply)</p> <p style="text-align: center; color: red;">disincfupprx__1</p> <p><input type="checkbox"/> 1. My child is not receiving disability income</p> <p><input type="checkbox"/> 2. Social Security Disability <span style="color: red;">disincfupprx__2</span></p> <p><input type="checkbox"/> 4. Supplemental security income (SSI) <span style="color: red;">disincfupprx__4</span></p> <p><input type="checkbox"/> 6. Other (please specify) <span style="color: red;">disincfupprx__6</span> <span style="color: red;">disincfupprx (txt)</span></p> <p><input type="checkbox"/> 99. I don't know <span style="color: red;">disincfupprx__99</span></p> <p style="font-size: small; color: blue;">Variable notes: For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)</p> <div style="border: 1px solid black; padding: 2px; width: 50px; margin: 0 auto; text-align: center;">88/Refused</div> <p style="text-align: center; color: red;">disincfupprx__88</p>	<p><i>If yes, is your child receiving disability income due to his/her burn injury?</i> <span style="color: red;">disincbrnprx</span></p> <p><input type="checkbox"/> 1. Yes, my child is receiving disability income due to his/her burn injury</p> <p><input type="checkbox"/> 2. No, my child is not receiving disability income due to his/her burn injury</p> <p><input type="checkbox"/> 77. Not applicable (not receiving disability income)</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="border: 1px solid black; padding: 2px; width: 50px; margin: 0 auto; text-align: center;">88/Refused</div>
<p><b>10. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)?</b> <span style="color: red;">physprobupprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="border: 1px solid black; padding: 2px; width: 50px; margin: 0 auto; text-align: center;">88/Refused</div>	

“The following question asks about your income. We appreciate this information because income is often related to health. For instance, we’d like to know if families with lower reported income have more trouble accessing health care, such as dental care or physical therapy. Having this information helps us advocate for better programs that serve people with burn injuries.”

11. Approximately what was your family’s total income for the last full year (total income of all family members living with you in your household)? (in U.S. dollars) **hinccatfupprx** 99/Unknown

- 1. Less than \$25,000
- 2. \$25,000-\$49,999
- 3. \$50,000-\$99,999
- 4. \$100,000-\$149,999
- 5. \$150,000-\$199,999
- 6. \$200,000 or more
- 7. Living outside the United States
- 77. Not applicable (e.g., living in an institution)
- 88. Prefer not to answer

*Variable notes:* Wording changed from "household total income" to "family's total income in 2022."

12. How many people are in your household? \_\_\_\_\_ **numhsfupprx**

88/Refused  
99/Unknown

13. Who is the primary sponsor of your child’s care currently? That is, who is paying for the majority of your child’s burn care costs? (Choose only one) **pay\_fupprx** 88/Refused

- 1. Medicare
- 2. Medicaid (DSHS)
- 3. Private insurance/HMO/PPO/Pre-paid/Managed
- 4. Worker’s compensation (L&I)
- 6. Champus/Tri-Care
- 7. Self-pay or indigent (public support)
- 9. VA
- 10. Other
- 11. Philanthropy (private support or private foundation or Shriners hospital)
- 77. Not applicable (no burn care costs)
- 99. I don’t know

**Interviewer Instructions:** *If the child is under 14 years old, you are finished with the interview. If the child is between 14 and 17 years old, please complete Section 14 below.*

Length of interview: \_\_\_\_\_

**If the child is under 14 years old, say, “is there anything else you would like to tell us?”**

“Thank you very much for sharing your experiences with us.”

<b>Section 14</b>	
<i>Interviewer Instructions: If the child is <b>between 14 and 17 years old</b>, please complete Section 14, below.</i>	
<b>Currently:</b>	
1. Does your child take personal responsibility for grooming when asked? <input type="checkbox"/> 1. Often <span style="color: red;">cip2prx</span> <input type="checkbox"/> 2. Sometimes <input type="checkbox"/> 3. Never	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 2px auto;">99/Unknown</div>
<b>Approximately how many times a month does your child usually participate in the following activities outside of your home?</b>	
2. Shopping <span style="color: red;">ci3prx</span> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 2px auto;">99/Unknown</div>
3. Leisure activities such as movies, sports, and restaurants. <span style="color: red;">ci4prx</span> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 2px auto;">99/Unknown</div>
4. Visiting friends or relatives <span style="color: red;">ci5prx</span> <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 2px auto;">99/Unknown</div>
5. When your child participate in leisure activities does he/she usually do this alone or with others? <input type="checkbox"/> 1. Mostly alone <span style="color: red;">ci6prx</span> <input type="checkbox"/> 2. Mostly with friends who have burn injuries <input type="checkbox"/> 3. Mostly with family members <input type="checkbox"/> 4. Mostly with friends who do not have burn injuries <input type="checkbox"/> 5. With a combination of family and friends <input type="checkbox"/> 77. Not applicable (no leisure activities)	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 2px auto;">99/Unknown</div>
6. Does your child have a best friend with whom he/she can confide? <span style="color: red;">ci7prx</span> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know <span style="color: red; font-size: small;">CIQ Social Integration Subscale Total Score Proxy: ciqsicprx</span>	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 0 auto;">88/Refused</div>
Length of survey: _____  "Is there anything else you would like to tell us?" _____ _____ _____  Thank you very much for sharing your experiences with us."	

## **BMS Pediatric Proxy 0-7 Interview Form I: Research Staff Instructions**

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

<b>Form I Administration:</b>	
<p><b>Who is responding to this questionnaire? (Select all that apply)</b></p> <p><input type="checkbox"/> 1. Mother or stepmother proxydis__1</p> <p><input type="checkbox"/> 2. Father or stepfather proxydis__2</p> <p><input type="checkbox"/> 3. Guardian proxydis__3</p> <p><input type="checkbox"/> 4. Other proxydis__4</p>	<p><b>What is the method of administration of this form? admin</b></p> <p><input type="checkbox"/> 1. In person interview</p> <p><input type="checkbox"/> 3. Telephone interview</p> <p><input type="checkbox"/> 5. Medical Record Review</p>
<p><b>What is the language of administration of this form? language</b></p> <p><input type="checkbox"/> 1. English</p> <p><input type="checkbox"/> 2. Spanish</p>	<p><b>Checklist of forms: Mark when each is complete status</b></p> <p><input type="checkbox"/> 1. Patient Status Form</p> <p><input type="checkbox"/> 2. Medical Record Abstraction Form</p> <p><input type="checkbox"/> 3. Form I</p>

**Introduction script** (Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

"Thank you for agreeing to participate in this study. The aim of the study is to learn about how children do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I'll be asking questions about your child's burn injury, his/her health, and other questions about him/her and people around him/her. Some questions ask about what things were like before your child's burn injury, other questions are about his/her health now. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip." Please let me know at any time if you have any questions."

## Burn Model System Hospital Discharge Survey

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ disintdate

“We’re going to go ahead and get started.”

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Section I</b>										
<i>Instructions: Please answer each question with a “yes” or “no”.</i>										
<i>If you answer “yes”, then please indicate to what extent this problem affects your child’s daily activities using these responses:</i>										
1 Not at all	2 To a very small extent	3 To a small extent	4 To a moderate extent	5 To a fairly great extent	6 To a great extent	7 To a very great extent				
Does your child have problems... Problem?				1	2	3	4	5	6	7
1. Seeing? <span style="color: red;">chcprox1, chcprox1a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hearing? <span style="color: red;">chcprox2, chcprox2a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Learning and understanding? <span style="color: red;">chcprox3, chcprox3a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <span style="color: red;">chcprox4, chcprox4a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Controlling emotions or behavior? <span style="color: red;">chcprox5, chcprox5a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. with Seizures or epilepsy? <span style="color: red;">chcprox6, chcprox6a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <span style="color: red;">chcprox7, chc7proxa</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. with Teeth and gums? <span style="color: red;">chcprox8, chc8proxa</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. with Digestion (eg reflux, vomiting, or constipation)? <span style="color: red;">chcprox9, chcprox9a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. with Type 1 or Type 2 diabetes? <span style="color: red;">chcprox10, chcprox10a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. with Growth? <span style="color: red;">chcprox11, chcprox11a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Sleeping? <span style="color: red;">chcprox12, chcprox12a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. with Repeated infections? <span style="color: red;">chcprox13, chcprox13a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. with Breathing (eg asthma)? <span style="color: red;">chcprox14, chcprox14a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)? <span style="color: red;">chcprox15, chcprox15a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)? <span style="color: red;">chcprox16, 16a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)? <span style="color: red;">chcprox17, 17a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain? <span style="color: red;">chcprox18, chcprox18a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Does your child have any other health problems? <span style="color: red;">chcprox19</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem: <span style="color: red;">chcprox19ot (text field)</span>					

### Pre-Injury History Section

“The next section of questions is about your child’s situation before the injury. Your answers will help us understand problems related to the injury. Later in the survey there will be some similar questions about after the burn injury.”

<b>Section 2</b>	
<p>1. Before your child’s burn injury, where was he/she living? (Choose only one) <span style="color: red;">resdencprx</span></p> <p> <input type="checkbox"/> 1. Private residence  <input type="checkbox"/> 2. Nursing home  <input type="checkbox"/> 4. Correctional institution  <input type="checkbox"/> 5. Hotel/motel  <input type="checkbox"/> 6. Homeless  <input type="checkbox"/> 7. Hospital                 </p>	<p style="font-size: small; color: blue;">Variable Notes: In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.</p> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">99/Unknown</div>
<p>2. What was your child’s zip code at the time of his/her burn injury? <span style="color: red;">ziprx_pre</span></p> <p> <input type="checkbox"/> 1 Not applicable (not living in U.S.)      <input type="checkbox"/> 2 Not applicable (homeless)                 </p> <p style="font-size: small; color: red; text-align: right;">Checkboxes correspond to variable "zippremisprx"</p> <p style="font-size: small; color: blue;">(code 99999 for unknown)</p>	
<p>3. Who was your child living with before his/her burn injury? (Choose all that apply)</p> <p> <input type="checkbox"/> 4. Parent or step-parent <span style="color: red;">livingapr_x__4</span>  <input type="checkbox"/> 5. Other relative (siblings, grandparents) <span style="color: red;">livingapr_x__5</span>  <input type="checkbox"/> 6. Others, not part of family <span style="color: red;">livingapr_x__6</span>  <input type="checkbox"/> 7. Guardian <span style="color: red;">livingapr_x__7</span> </p>	<p style="font-size: small; color: blue;">Variable notes: For each variable, 0 = "no"(not checked) and 1 = "yes" (checked)</p> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">livingapr_x__88</div> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">99/Unknown</div> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">livingapr_x__99</div>
<p>4. Was your child enrolled in school at the time of his/her burn injury? <span style="color: red;">schoolprx</span></p> <p> <input type="checkbox"/> 1. Yes, in school  <input type="checkbox"/> 2. No, not in school                 </p>	<p style="color: blue;">If your child was not enrolled in school at the time of his/her burn injury, why not? <span style="color: red;">whynotprx</span></p> <p> <input type="checkbox"/> 0 Not school age  <input type="checkbox"/> 2 Medical problems  <input type="checkbox"/> 4 Emotional/social reasons  <input type="checkbox"/> 7 Personal choice  <input type="checkbox"/> 8 Other  <input type="checkbox"/> 77 Not applicable (going to school)  <input type="checkbox"/> 99 I don’t know                 </p> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">88/Refused</div>
<p>5. Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group?</p> <p> <input type="checkbox"/> 1. Above the grade level he/she should be for his/her age <span style="color: red;">gradelvlprx</span>  <input type="checkbox"/> 2. At the grade level he/she should be for his/her age  <input type="checkbox"/> 3. Lower than the grade level he/she should be for his/her age  <input type="checkbox"/> 77. Not applicable  <input type="checkbox"/> 99. I don’t know                 </p>	<div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; float: right; width: fit-content;">99/Unknown</div>
<p>6. In school, has your child ever been classified as a special education student? <span style="color: red;">speducdisprx</span></p> <p> <input type="checkbox"/> 1. Yes  <input type="checkbox"/> 2. No  <input type="checkbox"/> 77. Not applicable  <input type="checkbox"/> 99. I don’t know                 </p>	

<p>7. Before his/her burn injury, did your child have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? <b>physprobpreprx</b></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused
<p>8. Before his/her burn injury, was your child ever told by a doctor that he/she had any of the following psychological issues (choose all that apply)? <b>psychlistprx</b></p> <p><input type="checkbox"/> 0. None/no psychological issues</p> <p><input type="checkbox"/> 1. Depression</p> <p><input type="checkbox"/> 2. Bipolar disorder</p> <p><input type="checkbox"/> 3. Anxiety</p> <p><input type="checkbox"/> 4. Post-Traumatic Stress Disorder (PTSD)</p> <p><input type="checkbox"/> 5. Schizophrenia/psychotic disorder</p> <p><input type="checkbox"/> 6. Other, please explain: <b>psychlistotprx (text field)</b></p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused

*Variable notes:*  
There are two other variables in the database, psychlistprx2 and psychlistprx3 with the same coding in case more than one or two issues were selected.

<b>Section 3</b>	
<p>1. In <b>the month before your child's burn injury</b> did he/she take <u>prescription</u> medication for pain on a regular basis? <b>pmedprx_pre</b></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused
<b>In the past 12 months...</b>	
<p>2. In the past 12 months, did your child take medication for being worried, tense, or anxious?</p> <p><input type="checkbox"/> 1. Yes <b>wmedprx_pre</b></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused
<p>3. In the past 12 months, did your child take medication for being sad, empty, or depressed?</p> <p><input type="checkbox"/> 1. Yes <b>smedprx_pre</b></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused
<p>4. Did your child receive psychological therapy or counseling in the last 12 months?</p> <p><input type="checkbox"/> 1. Yes <b>psychtrprx</b></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	88/Refused

## Post-Injury History Section

“All the questions you just answered were about your child and the time before your child’s burn injury. Next I have some some questions about your child and his/her situation after his/her burn injury.”

### Section 4

<p>1. Is your child of Hispanic, Latino, or Spanish Origin? <b>ethnicity</b></p> <p><input type="checkbox"/> 1. Yes, Hispanic, Latino, or Spanish origin</p> <p><input type="checkbox"/> 2. No, not of Hispanic, Latino, or Spanish origin</p> <p><input type="checkbox"/> 88. Prefer not to answer</p>	99/Unknown
<p>2. What is your child’s race? <b>race</b></p> <p><input type="checkbox"/> 1. African-American or Black</p> <p><input type="checkbox"/> 2. Asian</p> <p><input type="checkbox"/> 3. White</p> <p><input type="checkbox"/> 4. American Indian/Alaskan Native</p> <p><input type="checkbox"/> 5. Native Hawaiian or Other Pacific Islander</p> <p><input type="checkbox"/> 6. More than one race ((please specify): <b>racemto (text field)</b></p> <p><input type="checkbox"/> 7. Some other race (please specify): <b>raceotr (text field)</b></p> <p><input type="checkbox"/> 88. Prefer not to answer</p>	99/Unknown

### Section 5

<p>1. After your child’s hospital discharge, where is/will he/she be living? (Choose only one)</p> <p><input type="checkbox"/> 1. Private residence <b>dislivsitprx</b></p> <p><input type="checkbox"/> 2. Nursing home</p> <p><input type="checkbox"/> 4. Correctional institution</p> <p><input type="checkbox"/> 5. Hotel/motel</p> <p><input type="checkbox"/> 6. Homeless</p> <p><input type="checkbox"/> 7. Hospital</p>	<p><b>88/Refused</b></p> <p><b>99/Unknown</b></p>
<p>2. Who will your child be living with after hospital discharge? (Choose all that apply)</p> <p><input type="checkbox"/> 4. Parent or step-parent <b>livhsdisprx__4</b></p> <p><input type="checkbox"/> 5. Other relative (siblings, grandparents) <b>livhsdisprx__5</b></p> <p><input type="checkbox"/> 6. Others, not part of family <b>livhsdisprx__6</b></p> <p><input type="checkbox"/> 7. Guardian <b>livhsdisprx__7</b></p>	<p><b>88/Refused</b></p> <p><b>99/Unknown</b></p> <p><i>Variable notes:</i> For each variable, 0 = "no"(not checked) and 1 = "yes" (checked)</p>
<p>3. How many years of education has your child completed? <b>educdisprx</b></p> <p><input type="checkbox"/> 0. Preschool completed</p> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 77. N/A, not school age</p>	<p><b>88/Refused</b></p> <p><b>99/Unknown</b></p>

“The following question asks about your income. We appreciate this information because income is often related to health. For instance, we’d like to know if families with lower reported income have more trouble accessing health care, such as dental care or physical therapy. Having this information helps us advocate for better programs that serve people with burn injuries.”

4. Approximately what was your family’s total income in the last full year before your burn injury (total income of all family members living with you in your household)? (in U.S. dollars) 99/Unknown

- 1. Less than \$25,000 hinccatpreprx
- 2. \$25,000-\$49,999
- 3. \$50,000-\$99,999
- 4. \$100,000-\$149,999
- 5. \$150,000-\$199,999
- 6. \$200,000 or more
- 7. Living outside the United States
- 77. Not applicable (e.g., living in an institution)
- 88. Prefer not to answer

5. How many people are in your household? \_\_\_\_\_ numhspreprx 88/Refused  
99/Unknown

6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) 88/Refused  
99/Unknown

*Variable notes:*  
For each variable, 0 = "no"(not checked) and 1 = "yes" (checked)

- 1. My child is not receiving disability income disinccdisprx\_\_1 88
- 2. Social Security Disability disinccdisprx\_\_2
- 4. Supplemental security income (SSI) disinccdisprx\_\_4 99
- 6. Other (please specify) disinccdisprx\_\_6 disinccdisprx (text field)
- 99. I don’t know disinccdisprx\_\_99

**Section 6**

**Interviewer Instructions:** *If the child is between 3 and 7 years old, please ask the following questions. Otherwise skip this section. Write in 88 for refused or 99 for unknown for this section.*

Indicate how much you agree or disagree:

In the four weeks before my child’s burn injury...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. My child’s life was going well. <span style="color: red;">papxy066pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My child’s life was just right. <span style="color: red;">papxy067pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My child had a good life. <span style="color: red;">papxy070pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. My child had what he/she wanted in life. <span style="color: red;">papxy071pre</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*Length of interview:* \_\_\_\_\_

“Is there anything else you would like to tell us?”

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“We’ll be contacting you in about 6 months to see how your child is doing. Thank you very much for sharing your experiences with us!”

## BMS Pediatric Proxy 0-7 Interview Form II: Research Staff Instructions

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

proxy\_\_1  
 proxy\_\_2  
 proxy\_\_3  
 proxy\_\_4

<b>Form II Administration:</b>	
<b>Who is responding to this questionnaire? (Select all that apply)</b> <input type="checkbox"/> 1. Mother or stepmother <input type="checkbox"/> 2. Father or stepfather <input type="checkbox"/> 3. Guardian <input type="checkbox"/> 4. Other	<b>Follow-up period <span style="color: red;">follow_up</span></b> <input type="checkbox"/> 1. 6-month follow-up <input type="checkbox"/> 2. 12 month follow-up <input type="checkbox"/> 3. 24 month follow-up <input type="checkbox"/> 4. 5 year follow-up
<b>What is the method of <span style="color: red;">admin_fup</span> administration of this form?</b> <input type="checkbox"/> 1. In person interview <input type="checkbox"/> 3. Telephone interview <input type="checkbox"/> 5. Medical Record Review	<b>What is the language of administration of this form? <span style="color: red;">language_fup</span></b> <input type="checkbox"/> 1. English <input type="checkbox"/> 2. Spanish
<b>What is the status of this follow-up assessment? <span style="color: red;">lostfolo</span></b> <input type="checkbox"/> 1. Some or all assessment done <input type="checkbox"/> 2. Death due to burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 3. Death due to non- burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 4. Unable to locate <input type="checkbox"/> 5. Refused this assessment <input type="checkbox"/> 6. Unable to test/med comp/incapable of responding <input type="checkbox"/> 7. Failed to respond <input type="checkbox"/> 8. Did not consent to future assessment/withdrew <input type="checkbox"/> 11. Incarcerated <input type="checkbox"/> 13. Still in hospital (not discharged yet) <input type="checkbox"/> 14. Unable to travel for assessment <input type="checkbox"/> 15. Death (unknown causes) (update date and cause of death on Patient Status Form)	<b>If follow-up status is "unable to locate," mark the best reason, below: <span style="color: red;">unabletolocate</span></b> <input type="checkbox"/> 1. Homeless at previous data collection <input type="checkbox"/> 2. International place of residence <input type="checkbox"/> 3. Participant is child who was/is in CPS custody or foster care and no contact information is available <input type="checkbox"/> 4. No known current contact info <input type="checkbox"/> 5. Other reasons <input type="checkbox"/> 6. Unable to contact due to Shriners Hospital regulations

## Burn Model System Follow-up Survey: Introduction

**Introduction Script** (replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

“Hi my name is \_\_\_\_ and I am calling from \_\_\_\_\_ to ask you some questions about how your child has been doing (since your injury)... or (since we last spoke with you on (last follow-up date)).

Thank you for continuing to participate in our study. The aim of the study is to learn about how children do after a burn injury. Your answers will help us understand the experiences of all people with burn injury and I appreciate your willingness to share those experiences. I’ll be asking questions about your child’s burn injury, his/her health, and other questions about your child and people around him/her. I will guide you as we go along. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.” Please let me know at any time if you have any questions.”

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ fup\_date

“As a reminder, your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.”

“We’re going to go ahead and get started.”

### Section I

1. Since your last research study questionnaire, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? peersupprx

88/Refused

- 1. Yes
- 2. No
- 77. Not applicable
- 99. I don’t know

<p>2. To your knowledge, in the last year has your child had COVID-19? <b>covidstatprx</b></p> <p>Or, since your last research study questionnaire if your child's burn was less than a year ago, has your child had COVID-19?</p> <p><input type="checkbox"/> 1. Yes <b>—————→</b></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> <p style="text-align: right; border: 1px solid black; padding: 2px;">88/Refused</p>	<p>(If yes), What month and year did your child have COVID-19? (if your child has had COVID-19 more than once, provide the month and year of his/her <u>first</u> illness)</p> <p>Month: <b>covidmonthprx</b></p> <p>Year: <b>covidyearprx</b></p> <p style="text-align: right; border: 1px solid black; padding: 2px;">88/Refused 99/Unknown</p> <p>What level of care did your child receive for COVID-19?</p> <p><input type="checkbox"/> 1. Did not seek medical care <b>covidcareprx</b></p> <p><input type="checkbox"/> 2. Received medical care but was not hospitalized</p> <p><input type="checkbox"/> 3. Was hospitalized</p> <p style="padding-left: 20px;">In the hospital... (if applicable) <b>covidventprx</b></p> <p style="padding-left: 40px;"><input type="checkbox"/> 1. He/she was NOT on a ventilator (breathing machine with tube down his/her throat)</p> <p style="padding-left: 40px;"><input type="checkbox"/> 2. He/she was on a ventilator</p> <p style="padding-left: 40px;"><input type="checkbox"/> 3. I don't know</p> <p style="text-align: right; border: 1px solid black; padding: 2px;">88/Refused</p>
<p>3. Since your last research study questionnaire, has your child received any of the following services at home or outpatient? (Choose all that apply)</p> <p><input type="checkbox"/> 1. No services <b>servicesprx__1</b></p> <p><input type="checkbox"/> 2. Occupational therapy <b>servicesprx__2</b></p> <p><input type="checkbox"/> 3. Physical therapy <b>servicesprx__3</b></p> <p><input type="checkbox"/> 4. Speech language pathology <b>servicesprx__4</b></p> <p><input type="checkbox"/> 5. Social work <b>servicesprx__5</b></p> <p><input type="checkbox"/> 6. Psychological services <b>servicesprx__6</b></p> <p><input type="checkbox"/> 7. Vocational services or child life services <b>servicesprx__7</b></p> <p><input type="checkbox"/> 99. I don't know <b>servicesprx__99</b></p> <p style="font-size: small; color: blue;">Variable note: For each variable, 0 ="no"(not checked) and 1= "yes" (checked)</p>	
<div style="border: 1px solid black; padding: 5px; margin: 5px auto; width: 80%;"> <p><i>If clarification is needed, say,</i> "Examples of occupational therapy include helping with adjusting to a school environment after injury. Examples of physical therapy include range of motion and walking exercises."</p> </div> <p style="text-align: right; border: 1px solid black; padding: 2px;">88/Refused <b>servicesprx__88</b></p>	
<p><b>Interviewer Instructions: If the child didn't receive any services OR if they didn't receive PT/OT, skip to #8 on page 4</b></p>	
<p>4. If yes to OT and/or PT, How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? (If you don't know exactly, use your best guess) <b>numtherprx</b></p> <p><input type="checkbox"/> 1. One</p> <p><input type="checkbox"/> 2. 2 to 4</p> <p><input type="checkbox"/> 3. 5 to 10</p> <p><input type="checkbox"/> 4. More than 10</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received) <b>—————→ skip to #8 on page 4</b></p> <p><input type="checkbox"/> 99. I don't know</p> <p style="text-align: right; border: 1px solid black; padding: 2px;">88/Refused</p>	
<p>If yes to OT and/or PT, Since your last research study questionnaire, <u>where</u> did your child receive his/her outpatient occupational or physical burn therapy?</p>	
<p>5. At the burn center? <b>ther_brn_ctrprx</b></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p> <p style="text-align: right; border: 1px solid black; padding: 2px;">88/Refused</p>	

<p>6. At any other facility? <span style="color: red;">ther_otrprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
<p>7. Using telehealth? (for example, meeting with his/her therapist using video conferencing)</p> <p><input type="checkbox"/> 1. Yes <span style="color: red;">telehlthprx</span></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
<p>8. Since your last research study questionnaire, has your child had any burn related surgeries (such as surgeries for open wounds or scar management)?</p> <p><input type="checkbox"/> 1. Yes <span style="font-size: 2em; color: black;">→</span></p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know <span style="color: red;">surgery_fuprx</span></p>	<p><i>(If your child <u>did</u> have burn related surgeries)</i> Has your child had any burn-related surgeries outside of this clinical center? <span style="color: red;">surgoutprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>

<b>Section 2</b>											
“Please answer each question with a “yes” or “no”. If you answer “yes”, then please indicate to what extent this problem affects your child’s daily activities using these responses:”											
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>											
1 Not at all	2 To a very small extent	3 To a small extent	4 To a moderate extent	5 To a fairly great extent	6 To a great extent	7 To a very great extent					
Does your child have problems...				Problem?	1	2	3	4	5	6	7
1. Seeing? <span style="color: red;">chcprox1, chcprox1a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hearing? <span style="color: red;">chcprox2, chcprox2a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Learning and understanding? <span style="color: red;">chcprox3, chcprox3a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <span style="color: red;">chcprox4, chcprox4a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Controlling emotions or behavior? <span style="color: red;">chcprox5, chcprox5a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. with Seizures or epilepsy? <span style="color: red;">chcprox6, chcprox6a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <span style="color: red;">chcprox7, chcprox7a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. with Teeth and gums? <span style="color: red;">chcprox8, chcprox8a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. with Digestion (eg reflux, vomiting, or constipation)? <span style="color: red;">chcprox9, chcprox9a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. with Type 1 or Type 2 diabetes? <span style="color: red;">chcprox10, chcprox10a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. with Growth? <span style="color: red;">chcprox11, chcprox11a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Sleeping? <span style="color: red;">chcprox12, chcprox12a</span>				<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Does your child have problems...	Problem?	1	2	3	4	5	6	7
13. with Repeated infections? <b>chcprox13, chcprox13a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. with Breathing (eg asthma)? <b>chcprox14, chcprox14a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)? <b>chcprox15, chcprox15a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)? <b>chcprox16, chcprox16a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)? <b>chcprox17, chcprox17a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain? <b>chcprox18, chcprox18a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Does your child have any other health problems? <b>chcprox19, chcprox19a</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem: <b>chcprox19ot (text field)</b>						

**Section 3**

For each of the following symptoms please rate how much of a problem they are for your child in general.

	Not at all = 0	A little bit = 1	Some-what = 2	Quite a bit = 3	Very much = 4	
Pain <b>bmspain</b>	<input type="checkbox"/>	88/Refused 99/Unknown				
Itching <b>bmsitch</b>	<input type="checkbox"/>	88/Refused 99/Unknown				

**Section 4**

1. Is your child **currently** taking prescription medication for pain on a regular basis? 88/Refused

1. Yes **pmedprx**

2. No

99. I don't know

---

2. Is your child **currently** taking prescription medication for itch on a regular basis? 88/Refused

1. Yes **imedprx**

2. No

99. I don't know

---

3. In the **past 12 months**, did your child take medication for being, worried, tense, or anxious? 88/Refused

1. Yes **wmedprx**

2. No

99. I don't know

4. In the **past 12 months**, did your child take medication for being sad, empty, or depressed?

1. Yes **smedprx**  
 2. No  
 99. I don't know

88/Refused

5. Since your last research study questionnaire, has your child received psychological therapy or counseling due to his/her burn injury? **psychtherprx**

1. Yes  
 2. No  
 99. I don't know

88/Refused

### Section 5

1. What is your child's current weight? (lbs) **wtfuprx**  I don't know

88/Refused

2. What is your child's current height? (feet/inches) **htfuprx**  I don't know

88/Refused

3. Where is your child currently living? (Choose only one) **resdencfuprx**

1. Private residence  
 2. Nursing home  
 4. Correctional institution  
 5. Hotel/motel  
 6. Homeless  
 7. Hospital

*Variable notes:* In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.

88/Refused

99/Unknown

4. What is your child's current zip code? **zipfuprx** \_\_\_\_\_

- 1 Not applicable (not living in U.S.)  2 Not applicable (homeless)  
 (code 99999 for unknown) *Checkboxes correspond to variable "zipfupmissprx"*

5. Who is your child currently living with? (Choose all that apply)

4. Parent or step-parent **livingafuprx\_\_4**  
 5. Other relative (siblings, grandparents) **livingafuprx\_\_5**  
 6. Others, not part of family **livingafuprx\_\_6**  
 7. Guardian **livingafuprx\_\_7**

88/Refused

livingafuprx\_\_88

99/Unknown

livingafuprx\_\_99

*Variable note:*

For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)

<p>6. What is your child's current school status?</p> <p><input type="checkbox"/> 1. In school <span style="color: red;">aschoolfuprx</span></p> <p><input type="checkbox"/> 2. Not in school <span style="font-size: 2em; font-weight: bold;">→</span></p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">99/Unknown</div>	<p><i>If your child isn't going to school, why not?</i></p> <p><input type="checkbox"/> 0 Not school age <span style="color: red;">whynotfuprx</span></p> <p><input type="checkbox"/> 1 Burn related</p> <p><input type="checkbox"/> 2 Other medical problems</p> <p><input type="checkbox"/> 4 Emotional/social reasons</p> <p><input type="checkbox"/> 7 Personal choice</p> <p><input type="checkbox"/> 8 Other</p> <p><input type="checkbox"/> 77 Not applicable (going to school)</p> <p><input type="checkbox"/> 99 I don't know</p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">88/Refused</div>
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7. Interviewer instructions: *If the child hadn't already returned to school before their last research study questionnaire, but the child is in school now, say:*  
 "What was your child's first date to return to school since his/her injury? (Please take your best guess if you don't know the exact date):" \_\_\_\_/\_\_\_\_/\_\_\_\_ retrndat

<p>8. How many years of education has your child completed? <span style="color: red;">educfuprx</span></p> <p><input type="checkbox"/> 0. Preschool completed</p> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 77. Not applicable (child is too young for school)</p>	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">88/Refused</div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">99/Unknown</div>
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<p>9. Is your child currently receiving <u>disability</u> income such as Social Security Disability?          (Choose all that apply)</p> <p style="text-align: center; color: red;"><span style="margin-right: 20px;">disincfuprx__1</span></p> <p><input type="checkbox"/> 1. My child is not receiving disability income</p> <p><input type="checkbox"/> 2. Social Security Disability <span style="color: red;">disincfuprx__2</span></p> <p><input type="checkbox"/> 4. Supplemental security income (SSI) <span style="color: red;">disincfuprx__4</span></p> <p><input type="checkbox"/> 6. Other (please <span style="color: red;">disincfuprx__6</span> specify) <span style="color: red;">disincfupoprx (text field)</span></p> <p><input type="checkbox"/> 99. I don't know <span style="color: red;">disincfuprx__99</span></p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">88/Refused</div> <p style="color: blue; font-size: 0.8em;"><u>Variable notes:</u>          For each variable, 0 = "no" (not checked) and 1 = "yes" (checked)</p>	<p><i>If yes, is your child receiving disability income due to his/her burn injury?</i> <span style="color: red;">disincbrnprx</span></p> <p><input type="checkbox"/> 1. Yes, my child is receiving disability income due to his/her burn injury</p> <p><input type="checkbox"/> 2. No, my child is not receiving disability income due to his/her burn injury</p> <p><input type="checkbox"/> 77. Not applicable (not receiving disability income)</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">88/Refused</div>
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<p>10. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? <span style="color: red;">physprobuprx</span></p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	<div style="border: 1px solid black; padding: 2px; width: fit-content; margin: 5px auto;">88/Refused</div>
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“The following question asks about your income. We appreciate this information because income is often related to health. For instance, we’d like to know if families with lower reported income have more trouble accessing health care, such as dental care or physical therapy. Having this information helps us advocate for better programs that serve people with burn injuries.”

11. Approximately what was your family’s total income for the last full year (total income of all family members living with you in your household)? (in U.S. dollars) **hinccatfupprx** 99/Unknown

1. Less than \$25,000  
 2. \$25,000-\$49,999  
 3. \$50,000-\$99,999  
 4. \$100,000-\$149,999  
 5. \$150,000-\$199,999  
 6. \$200,000 or more  
 7. Living outside the United States  
 77. Not applicable (e.g., living in an institution)  
 88. Prefer not to answer

*Variable notes:* wording changed from "household total income" to "family's total income" in 2022.

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12. How many people are in your household? **numhsfupprx** 88/Refused  
99/Unknown

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13. Who is the primary sponsor of your child’s care currently? That is, who is paying for the majority of your child’s burn care costs? (Choose only one) **pay\_fupprx** 88/Refused

1. Medicare  
 2. Medicaid (DSHS)  
 3. Private insurance/HMO/PPO/Pre-paid/Managed  
 4. Worker’s compensation (L&I)  
 6. Champus/Tri-Care  
 7. Self-pay or indigent (public support)  
 9. VA  
 10. Other  
 11. Philanthropy (private support or private foundation or Shriners hospital)  
 77. Not applicable (no burn care costs)  
 99. I don’t know

*Variable Notes:*  
 In 2018, the categories HMO/PPO/Prepaid/Managed Care and Private insurance (previously categories 3 and 5) were collapsed into one broader category.  
 --In 2018, the categories indigent and self-pay (previously categories 7 and 8) were collapsed into one broader category.  
 --In 2018 clarification was added to #11 that it is the category to select when care was paid for by Shriners.  
 --When changes were made in 2018, existing data was pulled and archived so categories that were collapsed could be expanded with historical data, if necessary.

<b>Section 6 Interviewer instructions:</b> Write in 88 for refused or 99 for unknown for this section.					
<b>The following questions ask about this child’s appearance:</b>					
	<b>Definitely true = 1</b>	<b>Mostly true = 2</b>	<b>Not sure = 3</b>	<b>Mostly false = 4</b>	<b>Definitely false = 5</b>
1. This child feels that the burn is unattractive to others. <b>bodyimp_1</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This child thinks that people would not want to touch him/her. <b>bodyimp_2</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. This child feels unsure of himself/herself among strangers. <b>bodyimp_3</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Changes in this child’s appearance have interfered with his/her relationships. <b>bodyimp_4</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 7**

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

Below is a list of activities. Please choose which response best describes your child's ability in those activities.

- Unable = Can't do, doesn't know how, or is too young = 1
- Hard = Does with a lot of help, extra time, or effort = 2
- A little Hard = Does with a little help, extra time or effort = 3
- Easy=Does with no help, extra time or effort, or child's skills are past this level= 4

(Please do not consider use of walking devices (walker, crutches or canes) unless specified.)

Please choose which answer best describes your child's abilities in the following activities.	Unable	Hard	A little hard	Easy
1. When lying on belly, turns head to both sides <span style="color: red;">pedi_2</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. Sits on floor without support of pillow or couch <span style="color: red;">pedi_3</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Walks while holding onto furniture or walls <span style="color: red;">pedi_4</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Walks outdoors on grass, mulch or gravel <span style="color: red;">pedi_6</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. When running, is able to go around people and objects <span style="color: red;">pedi_7</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

PEDI Total Score Variable: pedi\_tot

*Instructions: If the child is younger than 3 you are finished with the interview after asking the next question below. If the child is **between the ages of 3 and 7**, continue with the rest of the survey on the last page.*

Length of interview: \_\_\_\_\_

If the child is under 3 years old, say,  
 "Is there anything else you would like to tell us?"

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You're done with the survey. Thank you very much for sharing your experiences with us."

**Section 8 (for children ages 3-7)***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please indicate how often or true the behavior is of your child.**

<u>NIH Toolbox Anger Proxy 3-7 T-Score Variable:</u> tbangtscore_proxy	<b>0=Never or not true</b>	<b>1=Sometimes or somewhat true</b>	<b>2=Often or very true</b>
1. Has temper tantrums or hot temper. pedproxang01	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Argues a lot with adults. pedproxang02	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is easily annoyed by others pedproxang06	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Gets back at people pedproxang08	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please indicate how often or true the behavior is of your child.**

	<b>0=Never or not true</b>	<b>1=Sometimes or somewhat true</b>	<b>2=Often or very true</b>
1. Is unhappy, sad or depressed. pedproxdep03	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Cries a lot. pedproxdep05	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Seems lonely. pedproxdep06	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Withdraws from peer activities. pedproxdep13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NIH Toolbox Sadness Proxy 3-7 T-Score Variable: tbsadtscore\_proxy**Section 9 (for children ages 3-7)***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

<b>Indicate how much you agree or disagree:</b> <u>NIH Toolbox General Life Satisfaction Proxy T-score Variable:</u> tbglstscoreprx	<b>1= Strongly disagree</b>	<b>2= Disagree</b>	<b>3= Neither agree nor disagree</b>	<b>4= Agree</b>	<b>5= Strongly agree</b>
1. My child's life is going well. papxy066	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My child's life is just right. papxy067	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My child has a good life. papxy070	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My child has what he/she wants in life. papxy071	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Length of interview: \_\_\_\_\_

Is there anything else you would like to tell us? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you very much for sharing your experiences with us!