

Burn Model System Survey Codebooks

This packet contains all codebooks of all forms used during the assessment of BMS longitudinal database participants.

The codebooks are the interview versions of the surveys, with variable names, information about the variables, and coding for each variable indicated in red text.

Numbers for response categories correspond to codes unless otherwise noted.

These Codebooks include:

1. Patient Status Codebook, used for all participants
2. Medical Record Abstraction Form I & II Codebook, used for all participants
3. Adult codebooks:
 - a. Review of Systems Discharge Codebook
 - b. Form I Adult Codebook
 - c. Review of Systems Follow-up Codebook
 - d. Form II Adult Codebook
4. Pediatric codebooks:
 - a. Form I Self Report 14-17
 - b. Form I Proxy 0-7
 - c. Form I Proxy 8-17
 - d. Form II Self Report 8-12
 - e. Form II Self Report 13-17
 - f. Form II Proxy 0-7
 - g. Form II Proxy 8-17

Codebooks serve as a resource for data interpretation and analysis; the questions and variable names that correspond to each question appear in the survey as it is administered, including instructions to the interviewer. To see the variables in list format rather than in the context of the surveys, consult the data dictionary.

Today's Date: ____ / ____ / ____

NewMSID (concatentation of site and MSID): newmsid

MSID: msid

Site (BMS center where care was received): **site**

- 1. Dallas—UTSW
- 3. Seattle—UW
- 5. Galveston—UTMB
- 6. Boston BMS

PS1. Primary admission criteria to Burn Model System: **criteria**

- 1. 10%+ TBSA 65+ yrs. w/ wound closure surgery
- 2. 20%+ TBSA 19-64 yrs. w/ wound closure surgery
- 3. 20%+ TBSA 0-18 yrs. w/ wound closure surgery
- 4. Elec. high volt./lightning w/ wound closure surgery
- 5. Hand, face, feet burn w/ wound closure surgery

PS2. Was patient alive at discharge? **alive_dc**

- 1. Yes
- 2. No

PS3. Consent at discharge for follow-up? **consented**

- 1. Yes, consented (*continue to PS4*)
- 2. No, did not consent/refused (*do not collect DOB or Date of Burn, skip PS4 and PS6*)
- 3. No, did not consent/missed (*do not collect DOB or Date of Burn, skip PS4 and PS6*)
- 4. Eligible but unable to consent (severe cognitive impairment due to dementia, TBI, etc) (*do not collect DOB or Date of Burn, skip PS4 and PS6*)
- 5. Eligible but unable to consent (language barriers) (*do not collect DOB or Date of Burn, skip PS4 and PS6*)

PS4. Date of birth: bth_date (yyyy/mm/dd) (*code 1900/09/09 for unknown*)

PS5. Year of birth: bth_year (yyyy) (*code 9999 for unknown*)

PS6. Date of burn injury: brn_date (yyyy/mm/dd) (*code 1900/09/09 for unknown*)

PS7. Year of burn injury: brn_year (yyyy) (*code 9999 for unknown*)

PS8. Gender: **gender**

- 1. Male
- 2. Female

PS9. Race and/or ethnicity. (*Interviewer Instructions: This item is administered as self-report in Form I, question #1 and #2 on page 20. If the participant consents, fill in this question using their self-report to the same question in Form 1. If the participant does not consent, fill in this question at the time of non-consent. If it is appropriate to ask based on interactions with the participant, 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.*)

a. Racial group? **race**

- 1. Black or African-American
- 2. Asian
- 3. Caucasian (white)
- 4. American Indian/Alaskan Native
- 5. Native Hawaiian or Other Pacific Islander
- 6. More than one race
- 7. Other (please specify): _____ **raceotr**
- 88. Declined to answer/Refused
- 99. Unknown

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*
 The BMS moved to these categories in 2015 to correspond more closely to the way the census captures race/ethnicity data

b. Ethnicity? **ethncity**

- 1. Hispanic or Latino
- 2. Not Hispanic or Latino
- 88. Declined to answer/Refused
- 99. Unknown

Source of PS9: **src_ethncity**

- 1. Medical record
- 2. Self report

The following questions are only for patients who were alive at discharge and consented to participate in the BMS research study.

PS10. Date of admission to Model System: _____ **enc_date** _____ (yyyy/mm/dd)
 (code 1900/09/09 for unknown)

PS11. Date of 2nd admission to Model System: _____ **enc_date_2nd** _____ (yyyy/mm/dd)

Coding:

- 1900/07/07 = not yet determined
- 1900/08/08 = not applicable (no 2nd admission)
- 1900/09/09 = unknown

PS12. Date of discharge from acute burn care (*does not include inpatient rehab*)

_____ **disch_date** _____ (yyyy/mm/dd)

Coding:

- 1900/07/07 = not yet determined
- 1900/09/09 = unknown

PS13. Date of 2nd discharge from acute burn care (if applicable, does not include inpatient rehab)

_____ disch_date_2nd _____ (yyyy/mm/dd)

Coding:

1900/07/07 = not yet determined

1900/08/08 = not applicable (no 2nd discharge)

1900/09/09 = unknown

PS14. Date consent form signed by participant _____ cnsnt_date _____ (yyyy/mm/dd)

Coding:

1900/07/07 = not yet determined

1900/08/08 = not applicable

1900/09/09 = unknown

Update this page when follow-up information is obtained after acute burn care discharge:

PS15. First date of return to work/school since injury: _____ retrndat _____ (yyyy/mm/dd)

Coding:

1900/07/07 = not yet determined

1900/08/08 = not applicable (no return to work or school)

1900/09/09 = unknown

PS16. Date of death: _____ dth_date _____ (yyyy/mm/dd)

Coding:

1900/07/07 = not yet determined

1900/08/08 = not applicable (Person Alive)

1900/09/09 = unknown

PS17. Primary Cause of Death ICD-9 Code: _____ . _____ deathcause1

Coding:

77777 - Expired: Cause Unknown;

88888 - Not Applicable (Person Alive);

99999 - Unknown

PS18. Secondary Cause of Death ICD-9 Code: _____ . _____ deathcause2

Coding:

77777 - Expired: Cause Unknown;

88888 - Not Applicable (Person Alive);

99999 - Unknown

PS19. Cause of Death E-Code (External Code): _____ . _____ deathcausee

Coding:

77777 - Expired: Cause Unknown;

88888 - Not Applicable (Person Alive);

99999 - Unknown

NewMSID_____

Today's Date: ____ ____ / ____ ____ / ____ ____

NewMSID _____

Instructions to BMS staff for use of this form: Fill out these items by using the information from the participant's medical record. This should be within 7 days (before or after) the time that 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.

MR1. Main cause of burn injury (primary etiology) **pretiol**

- 1. Fire/flame
- 2. Scald
- 3. Contact with hot object
- 4. Grease
- 5. Tar
- 6. Chemical
- 7. Hydrofluoric acid
- 8. Electricity
- 9. Radiation
- 10. UV light
- 11. Other burn
- 15. Flash burn
- 99. Unknown

Source of MR1: **src_pretiol**

- 1. Medical record
- 2. Self report

MR2. Space/place of burn injury: **placeinj**

- 1. Closed/indoors
- 2. Open/outdoors
- 99. Unknown

Source of MR2: **src_placeinj**

- 1. Medical record
- 2. Self report

NewMSID_____

MR3. Location of burn injury: **locinj**

1. Patient's home
2. Other private dwelling
3. Patient's place of work
4. Other building or structure
5. Conveyance (auto, plane, etc)
6. Other
99. Unknown

Source of MR3: **src_locinj**

1. Medical record
2. Self report

MR4. Circumstances of burn injury: **circinj**

1. Non-intentional employment related
2. Non-intentional non-work related (*choose this category if employment and/or recreation do not apply*)
3. Non-intentional recreation
4. Non-intentional non-specified (*choose this category if there is no information on circumstances other than non-intentional*)
5. Suspected assault-domestic
6. Suspected assault-non domestic
7. Suspected self-inflicted/suicide
8. Suspected arson
99. Unknown

Source of circumstances of burn injury: **src_circinj**

1. Medical record
2. Self report

MR5. Disposition: **disposn**

1. Died, burn related
2. AMA/Unable to complete treatment
3. Discharged, patient home
4. Discharged, other home (includes hospital owned apartments)
6. Discharged, extended care facility
8. Discharged, other rehab facility (not model system)
9. Discharged, institution
10. Discharged, drug/alcohol treatment center
11. Discharged, shelter
12. Discharged, street
13. Died, non-burn related
14. Other
99. Unknown

Source of disposition: **src_disposn**

1. Medical record
2. Self report

Note:

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.

NewMSID_____

MR6. Primary sponsor of care at hospital discharge, or who is paying for the majority of burn care costs (choose only one)? **pay_dc**

- 1. Medicare
- 2. Medicaid (DSHS)
- 3. Private insurance/HMO/PPO/Pre-paid/Managed Care
- 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)
- 99. Unknown

--Coding option 2, parenthetical statement (DSHS) added with new Forms in 2015
 Coding option 6, Tri-Care added with new Forms in 2015
 --Coding option 8, parenthetical statement amended and "charity care" added with new Forms in 2015

Notes: 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.

MR7. Total number of days on inpatient rehab unit: **rhb_days** _____ (code 999 for unknown)
(Separate from ICU and burn service days)

MR8. Inhalation injury? **inhalinj**

- 1. Yes
- 2. No
- 99. Unknown

MR9. Other injury (excluding inhalation injury)? **othrinj**

- 1. Yes
- 2. No
- 99. Unknown

Parts of the body burned:

MR10. Head/Face/Neck **hnbrn**

- 1 Yes
- 2. No
- 99. Unknown

Notes:
"Face" added to variable with new Forms in 2015

MR11. Trunk (back, chest, abdomen) **trnkbrn**

- 1. Yes
- 2. No
- 99. Unknown

Notes:
Parenthetical statement (back, chest, abdomen) added to variable with new Forms in 2015

MR12. Perineum (buttock, genitals) **peribrn**

- 1. Yes
- 2. No
- 99. Unknown

Notes:
Parenthetical statement (buttock, genitals) added to variable with new Forms in 2015

NewMSID_____

MR13. Shoulder/Upper Arm/Elbow **suebrn** (variable name prior to 1/15, with arm data, was **armbrn**)

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR14. Forearm (includes wrist) **farmbrn** (variable name prior to 1/15, with arm data, was **armbrn**)

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR15. Hand **handbrn**

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR16. Leg **legbrn**

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR17. Foot **footbrn**

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

Parts of body grafted:MR18. Head/Face/Neck **hngrft**

1. Yes 2. No 99. Unknown

Notes:

"Face" added to variable with new Forms in 2015

MR19. Trunk (back, chest, abdomen) **trnkgrft**

- 1 Yes 2. No 99. Unknown

Notes:

Parenthetical statement (back, chest, abdomen) added to variable with new Forms in 2015

MR20. Perineum (buttock, genitals) **perigrft**

- 1 Yes 2. No 99. Unknown

Notes:

Parenthetical statement (buttock, genitals) added to variable with new Forms in 2015

MR21. Shoulder/Upper Arm/Elbow **suegrft** (variable name prior to 1/15, with arm data, was **armgrft**)

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR22. Forearm (includes wrist) **farmgrft** (variable name prior to 1/15, with arm data, was **armgrft**)

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

NewMSID_____

MR23. Hand **handgrft**

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR24. Leg **leggrft**

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR25. Foot **footgrft**

1. Right 3. Bilateral 99. Unknown
 2. Left 4. None

MR26. Total body surface area burned (percent): **tbsabr** (XX.X) (code 999 for unknown)MR27 Total body surface area grafted (percent): **tbsagrft** (XX.X) (code 999 for unknown)MR28. Days on ventilator: **daysgrft** (code 999 for unknown)MR29. Number of trips to the operating room since injury (other than dressing changes), burn or non-burn related: **numtrpor** (code 999 for unknown)MR30. Tracheostomy? **trach**

- 1 Yes 2. No 99. Unknown

Notes:**New variable added with new Forms in 2015**MR31. Documented range of motion deficits **romdef** (previously collected variable was **contrctr**)

1. Yes
 2. No
 3. Not evaluated
 99. Unknown

MR32. Amputation(s) due to burn at discharge? **amputbrn**

- 1 Yes 2. No 99. Unknown

MR33. Upper extremity amputation (choose all that apply) **amput1**

1. Yes, above elbow right **amput1__1**
 2. Yes, above elbow left **amput1__2** 0 = checked
 3. Yes, above elbow bilateral **amput1__3** 1 = not checked
 4. Yes, below elbow right **amput1__4**
 5. Yes, below elbow left **amput1__5**
 6. Yes, below elbow bilateral **amput1__6**
 7. Yes, digits only right **numudgtr** (fill in # of digits) **amput1__7**
 (Thumb amputated? **thumb** 1 Yes 2 No)
 8. Yes, digits only left **numudgtl** (fill in # of digits) **amput1__8**
 (Thumb amputated? **thumb** 1 Yes 2 No)

NewMSID_____

9. Yes, digits only bilateral numudgtb (fill in # of digits) amput1__9
 (Thumbs amputated? thumbb 1 Yes 2 No)
10. No amput1__10
99. Unknown amput1__99

0 = checked
 1 = not checked

Notes:

New variable added with new Forms in 2015

MR34. Lower extremity amputation (*choose all that apply*) amput2

1. Yes, above knee right amput2__1
2. Yes, above knee left amput2__2
3. Yes, above knee bilateral amput2__3
4. Yes, below knee right amput2__4
5. Yes, below knee left amput2__5
6. Yes, below knee bilateral amput2__6
7. Yes, digits only right numldgtr (fill in # of digits) amput2__7
8. Yes, digits only left numldftl (fill in # of digits) amput2__8
9. Yes, digits only bilateral numldgtb (fill in # of digits) amput2__9
10. Transmetatarsal right (partial foot amputation right) amput2__10
11. Transmetatarsal left (partial foot amputation left) amput2__11
12. Transmetatarsal bilateral (partial foot amputation bilateral) amput2__12
13. No amput2__13
99. Unknown amput2__99

0 = not checked
 1 = checked

Notes:

New variable added with new Forms in 2015

MR35. Hand dominance handdom

1. Right 3. Ambidextrous
 2. Left 99. Unknown

Notes:

New variable added with new Forms in 2015

MR36. MRSA/MDRO positive during acute hospitalization (multi-resistant gram negative/gram positive/fungal/including mold)? mrsa

- 1 Yes 2. No 99. Unknown

Notes:

New variable added with new Forms in 2015

MR37. Heterotopic ossification at discharge? hodc

- 1 Yes 2. No 99. Unknown

MR38. Height at admission (centimeters) heightad (code 999 for unknown)MR39. Weight at admission (kilograms) weightad (code 999 for unknown)MR40. Height at discharge (centimeters) htdc (code 999 for unknown)

NewMSID_____

MR41. Weight at discharge (kilograms) _____ wtdc _____ (code 999 for unknown)

MR42. Exposed bone at discharge? bone_exp

- 1. Yes
- 2. No
- 99. Unknown

Notes:

Time period "at discharge" added to question with new Forms in 2015

MR43. Location of exposed bone at discharge locbexp

- 1. Head
- 2. Torso
- 3. Upper extremity
- 4. Lower extremity
- 5. Other
- 77. Not applicable
- 99. Unknown

Notes:

New variable added with new Forms in 2015

MR44. Exposed tendon at discharge? tendon_exp

- 1. Yes
- 2. No
- 99. Unknown

Notes:

Time period "at discharge" added to question with new Forms in 2015

MR45. Location of exposed tendon at discharge loctexp

- 1. Head
- 2. Torso
- 3. Upper extremity
- 4. Lower extremity
- 5. Other
- 77. Not applicable
- 99. Unknown

Notes:

New variable added with new Forms in 2015

NewMSID _____

<u>Co-Morbidities List</u>	Yes	No	Missing/ Unknown
Has the participant ever been diagnosed with...			
1. Hypertension or high blood pressure? highbp	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
2. Congestive heart failure? conghf	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
3. Myocardial infarction or heart attack? heartatk	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
4. Heart arrhythmias? heartar	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
5. Stroke? stroke	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
6. Emphysema or asthma or COPD? copd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
7.High blood cholesterol? highchol	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
8. Diabetes, high blood sugar, or sugar in the urine? diabetes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
9. Pneumonia? pneum	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
10. Liver disease (such as hepatitis)? hepat	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
11.Rheumatoid arthritis? rheum	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
12.Osteoarthritis? osteo	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
13.Sleep disorder like sleep apnea? sleepdis	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
14.Cataracts? catar	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
15.Chronic pain? chronpa	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
16.Dementia of some kind, like Alzheimer's? alz	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
17.Parkinson's disease? parkd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
18.Alcoholism? etohadd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
19.Drug addiction? drugadd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
20.Depression? depress	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
21.Anxiety? anx	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
22.Panic attacks? panic	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
23.Bipolar disorder or manic-depression? bipol	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
24.Attention deficit disorder (ADD/attention deficit hyperactivity disorder (ADHD)? adhd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
25.Obsessive-compulsive disorder? ocd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
26.PTSD (post-traumatic stress disorder)? ptsd	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
27. Spinal cord injury? sci	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
28. Traumatic brain injury? tbi	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99

NewMSID_____

Pain Medication Data Collection Table

(only pain medication prescribed at discharge OR within 30 days of discharge needs to be collected)

- 0 = not checked 1 = checked
- 0. No pain medication pmed_dis___0
 - 1. Methadone pmed_dis___1
 - 2. Codeine pmed_dis___2
 - 3. Hydrocodon (Norco, Vicoden) pmed_dis___3
 - 4. Oxycodone (Percodet, OxyContin) pmed_dis___4
 - 5. Hydromorphone (Dilaudid) pmed_dis___5
 - 6. Fentanyl (Duragesic) pmed_dis___6
 - 7. Morphine pmed_dis___7
 - 8. Acetaminophen with codeine (Tylenol #3) pmed_dis___8
 - 9. Gabapentin (Neurontin) pmed_dis___9
 - 10. Amitriptyline pmed_dis___10
 - 99. Unknown pmed_dis___99

Name of Pain Medication (prescribed at discharge), if other than above (text field for name of medication)	
1.	meddis1
2.	meddis2
3.	meddis3
4.	meddis4
5.	meddis5
6.	meddis6
7.	meddis7
8.	meddis8
9.	meddis9
10.	meddis10
11.	meddis11
12.	meddis12

Today's Date: ____ / ____ / ____ **disintdate**
(NOTE: FIRST PAGE IS FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: start_time

1. What is the method of administration of this form? **admin**

1. In person interview
2. Mail
3. Telephone interview
4. Online
5. Medical record review

2. What is the language of administration of this form? **language**

1. English
2. Spanish
3. Other

3. Checklist of forms: mark when each is complete **status**

1. Patient Status Form **status__1**
2. Medical Record Abstraction Form **status__2** 0 = not checked
3. Review of Systems Checklist Form **status__3** 1 = checked
4. Form I **status__4**

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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.

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) next to that item.

Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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." We're going to get started with the survey. Please let me know at any time if you have any questions.

Health Status

***Review of Systems:** Interviewer Instructions: Throughout the survey, do not read section headings in Times New Roman font and italics aloud to participants. Skip to the next section (Pre-Injury History on page 3) if the participant has already filled out the Review of Systems. If the participant doesn't want to answer a question, circle the number 88 that appears to the right of each item.*

Please answer each question as it relates to your <u>current</u> health:				
1. Hearing loss? hlossdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
2. Change in voice? voicedis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
3. Vision problems not corrected by glasses or contact lenses? visiondis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
4. Eyelid problems? eyeliddis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
5. Excessive tearing of the eyes? teardis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
6. Difficulty with memory? memorydis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
7. Difficulty with thought processing? thoughdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
8. Numbness, pins and needles or burning sensations in your burn scar? numbscdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
9. Numbness, pins and needles or burning sensations in your hands? numbhdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
10. Numbness, pins and needles or burning sensations in your feet? numbfdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
11. Trouble with your balance? tbalandis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
12. Varicose veins? varveindis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
13. Swollen feet or legs? swflegdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
14. Swollen hands or arms? swharmdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
15. Skin cancer? skincancdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
16. Joint pain? jpaindis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
17. Have you ever been pregnant or fathered a child? preg_fathdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
18. Blood clots in legs or lungs? bcleglungdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
19. Cold intolerance? cintoldis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
20. Excessive sweating? exsweatdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused
21. Difficulty in hot environments? difhotdis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 99 Don't know	88/Refused

Pre-Injury History

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.

Satisfaction with Life: PRE-BURN

Here are 5 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	Dis-agree =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: sl1_pre	<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: sl2_pre	<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: sl3_pre	<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: sl4_pre	<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
5. In the 4 weeks before my burn, if I could have lived my life over, I would have changed almost nothing: sl5_pre	<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

Satisfaction with Life Total Score: **swlscore_pre**

CIO: PRE-BURN

The next questions I have are about activities you might have participated in before your burn injury.

During the 4 weeks before your burn:

1: Who usually looked after your personal finances, such as banking and paying bills? **cia2_pre**

- | | |
|---|---|
| 1. <input type="checkbox"/> Yourself alone | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Yourself and someone else | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Someone else | |

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. <input type="checkbox"/> Never | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> 1-4 times | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> 5 or more times | |

3: Leisure activities such as movies, sports, and restaurants. **cia4_pre**

- | | |
|---|---|
| 1. <input type="checkbox"/> Never | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> 1-4 times | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> 5 or more times | |

4: Visiting friends or relatives **cia5_pre**

- | | |
|---|---|
| 1. <input type="checkbox"/> Never | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> 1-4 times | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> 5 or more times | |

During the 4 weeks before your burn:

5: When you participated in leisure activities did you usually do this alone or with others?

cia6_pre 88. Declined to answer/Refused

- | | |
|---|--------------------------------------|
| 1. <input type="checkbox"/> Mostly alone | 99. <input type="checkbox"/> Unknown |
| 2. <input type="checkbox"/> Mostly with friends who have burn injuries (N/A for Form I) | |
| 3. <input type="checkbox"/> Mostly with family members | |
| 4. <input type="checkbox"/> Mostly with friends who do not have burn injuries | |
| 5. <input type="checkbox"/> With a combination of family and friends | |
| 77. <input type="checkbox"/> Not applicable (no leisure activities) | |

6: Did you have a best friend with whom you confided? **cia7_pre**

- | | |
|---------------------------------|---|
| 1. <input type="checkbox"/> Yes | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> No | 99. <input type="checkbox"/> Unknown |

Community Integration Questionnaire Social Integration Score: **ciqsic_pre**

VR-12: PRE-BURN

INSTRUCTIONS: These questions ask you for your views about your health. This information will keep track of how you feel and how well you are able to do your usual activities. Answer every question by choosing a response. If you are unsure how to answer a question, please give your answer the best you can.

(Interviewer Instructions: Circle one number on each line)

1. In general, would you say your health before your burn was: **vr12pre1**

EXCELLENT	VERY GOOD	GOOD	FAIR	POOR	
1	2	3	4	5	88/Refused 99/Unknown

2. The following questions are about activities you might do during a typical day. Did **your health limit you** in these activities before your burn injury? If so, how much?

**YES,
LIMITED
A LOT** **YES,
LIMITED
A LITTLE** **NO,
NOT
LIMITED
AT ALL**

a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? **vr12pre2a**

1 2 3 88/Refused
99/Unknown

b. Climbing **several** flights of stairs? **vr12pre2b**

1 2 3

3. During the 4 weeks before your burn, did you have any of the following problems with your work or other regular daily activities **as a result of your physical health**?

**NO,
NONE
OF THE
TIME** **YES,
A
LITTLE
OF THE
TIME** **YES,
SOME
OF THE
TIME** **YES,
MOST
OF THE
TIME** **YES,
ALL
OF THE
TIME**

a. **Accomplished less** than you would like. **vr12pre3a**

1 2 3 4 5 88/Refused
99/Unknown

b. Were limited in the **kind** of work or other activities. **vr12pre3b**

1 2 3 4 5 88/Refused
99/Unknown

4. During the 4 weeks before your burn, did you have any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	NO, NONE OF THE TIME	YES, A LITTLE OF THE TIME	YES, SOME OF THE TIME	YES, MOST OF THE TIME	YES, ALL OF THE TIME	
a. Accomplished less than you would like. <i>vr12pre4a</i>	1	2	3	4	5	88/Refused 99/Unknown
b. Didn't do work or other activities as carefully as usual. <i>vr12pre4b</i>	1	2	3	4	5	88/Refused 99/Unknown

5. During the 4 weeks before your burn, how much did **pain** interfere with your normal work (including both work outside the home and house work)? *vr12pre5*

NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	2	3	4	5	88/Refused 99/Unknown

These questions are about how you felt and how things were for you the four weeks before your burn. For each question, please give the one answer that comes closest to the way you felt.

6. How much of the time during the 4 weeks before your burn:

	ALL OF THE TIME	MOST OF THE TIME	A GOOD BIT OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME	
a. Did you feel calm and peaceful ? <i>vr12pre6a</i>	1	2	3	4	5	6	88/Refused 99/Unknown
b. Did you have a lot of energy ? <i>vr12pre6b</i>	1	2	3	4	5	6	88/Refused 99/Unknown
c. Did you feel downhearted and blue ? <i>vr12pre6c</i>	1	2	3	4	5	6	88/Refused 99/Unknown

7. During the 4 weeks before your burn, how much of the time did your **physical health or emotional problems** interfere with your social activities (like visiting with friends, relatives, etc.)? **vr12pre7**

ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME
1	2	3	4	5

88/Refused
99/Unknown

VR-12 Mental Health Component Score: Pre Total Score Variable: **mcs_vr12_pre**

VR-12 Physical Health Component Score: Pre Total Score Variable: **pcs_vr12_pre**

Pain Medication

1. In the month before your burn injury did you take prescription medication for pain on a regular basis? **pmed_pre**

- 1. Yes
- 2. No

88. Declined to answer/Refused
99. Unknown

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

- 1. Yes
- 2. No

88. Declined to answer/Refused
99. Unknown

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

- 1. Yes
- 2. No

88. Declined to answer/Refused
99. Unknown

4. Did you receive psychological therapy or counseling in the last 12 months? **psychtr**

- 1. Yes
- 2. No

88. Declined to answer/Refused
99. Unknown

Pre-Injury Demographics

1. Before your burn injury, where were you living? (Choose only one) **resdenc**

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

Note: 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? _____ **zip_pre**
(Code 99999 for unknown, code 00000 for Mexico, code 77777 for not applicable/homeless)

Added to data collection forms in 2015.

3. Who were you living with before your burn injury? (Choose all that apply)

- | | |
|---|--|
| 1. <input type="checkbox"/> Alone livinga__1 | 88. <input type="checkbox"/> Declined to answer/Refused livinga__88 |
| 2. <input type="checkbox"/> Spouse/partner/significant other livinga__2 | 99. <input type="checkbox"/> Unknown livinga__99 |
| 3. <input type="checkbox"/> Friend livinga__3 | |
| 4. <input type="checkbox"/> Parent or step-parent livinga__4 | |
| 5. <input type="checkbox"/> Other relative (siblings, grandparents) livinga__5 | 0 = not checked |
| 6. <input type="checkbox"/> Others, not part of family livinga__6 | 1 = checked |
| 7. <input type="checkbox"/> Guardian livinga__7 | |
| 8. <input type="checkbox"/> Young children livinga__8 | |
| 9. <input type="checkbox"/> Adult children livinga__9 | |

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn injury?". Also changed variable so that multiple answers were acceptable.

4. What was your marital status at the time of your burn injury? (Choose only one) **marstatpre**

- | | |
|--|---|
| 1. <input type="checkbox"/> Married; living common-law or with a partner | |
| 2. <input type="checkbox"/> Separated | 88. <input type="checkbox"/> Declined to answer/Refused |
| 3. <input type="checkbox"/> Divorced | 99. <input type="checkbox"/> Unknown |
| 4. <input type="checkbox"/> Widowed | |
| 5. <input type="checkbox"/> Single (not married) | |

Added to data collection forms in 2015. Old archived data from marital status (1-single, 2-married, 3-partner) was converted to new coding and old data was imported.

5. Approximately what was your household's total income in the last full year before your burn injury (total income of all members of the household)? **hinccatpre**

If clarification is needed about the reason this question is asked, say, "Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds."

If clarification about currency is needed, say, "these categories are in U.S. dollar amounts."

- | | |
|--|---|
| 1. <input type="checkbox"/> Less than \$25,000 | |
| 2. <input type="checkbox"/> \$25,000-\$49,999 | 88. <input type="checkbox"/> Declined to answer/Refused |
| 3. <input type="checkbox"/> \$50,000-\$99,999 | 99. <input type="checkbox"/> Unknown |
| 4. <input type="checkbox"/> \$100,000-\$149,999 | |
| 5. <input type="checkbox"/> \$150,000-\$199,999 | |
| 6. <input type="checkbox"/> \$200,000 or more | |
| 7. <input type="checkbox"/> Living outside the United States | |
| 77. <input type="checkbox"/> Not applicable (e.g., living in an institution) | |

6. How many people are in your household? **numhspre**

(Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

7. In the year prior to your burn injury, how many months did you work at a regular job? _____ (fill in # of months)
mrjobpre

(Interviewer prompt: If necessary, say, "This would include any job for which you were paid at least minimum wage, and worked without the help of another person like a job coach or therapist")

- 0. Less than 1 month
- 77. Not applicable (did not work in the past year)
- 88. Declined to answer/Refused
- 99. Unknown

Added to data collection forms in 2015.

8. Before your burn (or the last time you worked, if the answer to the last question was less than 1 month), what was your primary occupation?

Occupation: **occpre**

Code: **occodepre**

Added to data collection forms in 2015.

Interviewer instructions: Ask this as an open-ended question. Fill out the blank with the occupation the participant states and then the code, found below.

- 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; 77 – Not Applicable; 88 – Declined to Answer/Refused; 99 – Unknown

9. What was your employment status at the time of your burn? (Choose only one) **employpre**

- 1. Working (*Interviewer instructions: continue with next question*)
- 2. Not working (looking for work)
- 3. Not working (not looking for work)
- 4. Homemaker/caregiver
- 5. Volunteer
- 6. Retired
- 88. Declined to answer/Refused
- 99. Unknown

→ *Interviewer instructions: skip to #11, below*

Old variable was named "employ".

Wording changed with shift to new forms 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".**

10. Before your burn, about how many hours a week did you work for pay? hpaypre

(Interviewer Instructions: fill in hours)

777. Not applicable (not employed)
888. Declined to answer/Refused
999. Unknown

Interviewer Instructions: Skip #11 and move on to #12 on the next page 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).

11. Approximately what was your individual income in the last full year before your burn injury?
iinccatpre

If clarification about currency is needed, say, "these categories are in U.S. dollar amounts."

- | | |
|--|---|
| 1. <input type="checkbox"/> Less than \$25,000 | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> \$25,000-\$40,999 | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> \$41,000-\$55,999 | |
| 4. <input type="checkbox"/> \$56,000-\$70,999 | |
| 5. <input type="checkbox"/> \$71,000-\$85,999 | |
| 6. <input type="checkbox"/> \$86,000-\$100,000 | |
| 7. <input type="checkbox"/> Greater than \$100,000 | |
| 8. <input type="checkbox"/> Living outside the United States | |
| 77. <input type="checkbox"/> Not applicable (no individual income) | |

Interviewer Instructions: Ask this question for both working and non-working participants.

12. Were you going to school at the time of your burn injury? **aschool**

- | | |
|---|---|
| 1. <input type="checkbox"/> In school | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Not in school | 99. <input type="checkbox"/> Unknown |

New variable added to adult forms, to take the place of the old variable for all participants, school.

Interviewer Instructions: Skip to #14 on this page if participant was working or going to school before the burn injury.

13. If you were not working or going to school at the time of your burn injury, why not? **whynot**

- | | |
|---|---|
| 1. <input type="checkbox"/> Burn related (This response is N/A for discharge) | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Medical problems other than your burn injury. | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Problems with employer | |
| 4. <input type="checkbox"/> Emotional/social | |
| 5. <input type="checkbox"/> Legal/jail | |
| 6. <input type="checkbox"/> Substance abuse | |
| 7. <input type="checkbox"/> Personal choice | |
| 8. <input type="checkbox"/> Other | |
| 9. <input type="checkbox"/> Retired Response option added with 2015 forms | |
| 10. <input type="checkbox"/> Homemaker/caregiver Response option added with 2015 forms | |
| 11. <input type="checkbox"/> Unemployed but actively seeking employment Response option added with 2015 forms | |
| 77. <input type="checkbox"/> Not applicable (working or going to school) Response option added with 2015 forms | |

14. Before the burn, did you have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? **physprobpre (this variable replaced "physdis" in 2015)**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

15. Before the burn, did you have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimppre**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

16. 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**

1. Depression
2. Bipolar disorder **0=No issue selected**
3. Anxiety
4. Post-Traumatic Stress Disorder (PTSD)
5. Schizophrenia/psychotic disorder
6. Other, please explain: _____ **psychlistot**

88. Declined to answer/Refused
99. Unknown

CAGE Alcohol use:

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**

Now I have a few questions about your alcohol and drug use. As a reminder, you can skip any question you don't want to answer.

Interviewer Instructions: *If the participant states they do not drink after the first question, you can fill in "No" for all 4 questions and skip to the next section.*

These items are asked and then coded into the total variables, below

In the past year...

1. Have you felt you needed to **C**ut down on your drinking? Yes (1) No (0)

2. Have people **A**nnoyed you by criticizing your drinking? Yes (1) No (0)

3. Have you ever felt **G**uilty about drinking? Yes (1) No (0)

4. Have you ever felt you needed a drink first thing in the morning (**E**ye-opener) to steady your nerves or to get rid of a hangover? Yes (1) No (0)

CAGE Drug use:

Interviewer Instructions: *If clarification is needed, say, "We are interested in learning more 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."*

Interviewer Instructions: *If the participant states they do not use drugs after the first question, you can fill in "No" for all four questions and skip to the next section.*

In the past year...

1. Have you ever felt you needed to **Cut** down on your drug use? Yes (1) No (0)

2. Have people **Annoyed** you by criticizing your drug use? Yes (1) No (0)

3. Have you ever felt **Guilty** about your drug use? Yes (1) No (0)

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? Yes (1) No (0)

Interviewer Instructions: Do not ask the following questions, but fill in by summing the responses (total number of "yes" responses), above.

Patient's history of alcohol abuse in the last 12 months: **etohabu**

- 1. Yes (C-A-G-E=2,3,4)
- 2. No (C-A-G-E=0,1)
- 88. Declined to answer/Refused
- 99. Unknown

Patient's history of drug abuse in the last 12 months: **drugabu**

- 1. Yes (C-A-G-E=2,3,4)
- 2. No (C-A-G-E=0,1)
- 88. Declined to answer/Refused
- 99. Unknown

Post-Injury Section

All the questions I just asked you were about the time before your burn injury. Now I'm going to ask you some of the same questions I just asked you, but this time I want you to answer about the time since the 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.

Pain

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

	0	1	2	3	4	5	6	7	8	9	10
How would you rate your pain on average? global07_dis	<input type="checkbox"/>										

No pain

Worst imaginable pain

Itch scale:

The next questions are about itching since your burn injury.

Currently, do you have any itching in the area of your burn, skin grafts, or donor sites? **itchscr_dis**

1. Yes
2. No (*Interviewer Instructions: skip to Demographics on page 14*)
88. Declined to answer/Refused
99. Unknown

1. Currently, how many hours a day are you itching? **itch1_dis**

1. Less than 6 hours a day
2. 6-12 hours a day
3. 12-18 hours a day
4. 18-23 hours a day
5. All day
77. Not applicable (no itching)
88. Declined to answer/Refused
99. Unknown

2. Please rate the intensity of your itching: **itch2_dis**

1. Not present
2. Mild
3. Moderate
4. Severe
5. Unbearable
77. Not applicable (no itching)
88. Declined to answer/Refused
99. Unknown

3. Has your itching related to the burn injury gotten better or worse since the injury? **itch3_dis**

1. Completely resolved
2. Much better, but still present
3. Little bit better, but still present
4. Unchanged
5. Getting worse
77. Not applicable (no itching)
88. Declined to answer/Refused
99. Unknown

4. Please rate the impact of your current itching on your sleep: **itch4_dis**

1. Never affects sleep
2. Occasionally delays falling asleep
3. Frequently delays falling asleep
4. Delays falling asleep and occasionally wakes me up at night
5. Delays falling asleep and frequently wakes me up at night
77. Not applicable (no itching)
88. Declined to answer/Refused
99. Unknown

DEMOGRAPHICS

This is the last section of the survey.

Interviewer Instructions: Use medical record for #1-3. Skip these questions unless self-report is best source, and record answer onto the Form I Medical Record Abstraction Form along with source of data.

1. What is your racial group? **race**
- 1. Black or African-American
 - 2. Asian
 - 3. Caucasian (white)
 - 4. American Indian/Alaskan Native
 - 5. Native Hawaiian or Other Pacific Islander
 - 6. More than one race
 - 7. Other (please specify): **raceotr**
88. Declined to answer/Refused
99. Unknown

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

2. What is your ethnicity? **ethnicity**
- 1. Hispanic or Latino
 - 2. Not Hispanic or Latino
88. Declined to answer/Refused
99. Unknown

3. What is your dominant hand? **handdom**
- 1. Left
 - 2. Right
 - 3. Ambidextrous
 - 99. Don't know

1. After your discharge, where 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
- 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.**

Variable added in 2015, in addition to living before hospital discharge variable.

2. Who will you be living with after hospital discharge? (Choose all that apply)
- 1. Alone **livhisdisprx__1**
 - 2. Spouse/partner/significant other **livhisdisprx__2**
 - 3. Friend **livhisdisprx__3**
 - 4. Parent or step-parent **livhisdisprx__4**
 - 5. Other relative (siblings, grandparents) **livhisdisprx__5**
 - 6. Others, not part of family **livhisdisprx__6**
 - 7. Guardian **livhisdisprx__7**
 - 8. Young children **livhisdisprx__8**
 - 9. Adult children **livhisdisprx__9**
88. Declined to answer/Refused **livhsdis__88**
99. Unknown **livhsdis__99**
- 0=Not checked
1=Checked**

3. How many years of education have you completed? (*Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, "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." If participant ties to count years rather than degree attained, use the prompt, "In other words, what is the highest level of education you have completed?"*) **edudis**

Interviewer Instructions: Ask the question as open-ended, and then mark the appropriate response below.

- | | |
|--|---|
| 1. <input type="checkbox"/> 1 year or less | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> 2 years | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> 3 years | |
| 4. <input type="checkbox"/> 4 years | |
| 5. <input type="checkbox"/> 5 years | |
| 6. <input type="checkbox"/> 6 years | |
| 7. <input type="checkbox"/> 7 years | |
| 8. <input type="checkbox"/> 8 years | |
| 9. <input type="checkbox"/> 9 years | |
| 10. <input type="checkbox"/> 10 years | |
| 11. <input type="checkbox"/> 11 or 12 years; no diploma | |
| 12. <input type="checkbox"/> High school diploma | |
| 13. <input type="checkbox"/> Work towards Associate's degree, vocational degree, or trade school diploma/certificate | |
| 14. <input type="checkbox"/> Associate's degree, vocational degree, or trade school diploma/certificate | |
| 15. <input type="checkbox"/> Work towards Bachelor's degree | |
| 16. <input type="checkbox"/> Bachelor's degree | |
| 17. <input type="checkbox"/> Work towards Master's degree | |
| 18. <input type="checkbox"/> Master's degree | |
| 19. <input type="checkbox"/> Work towards doctorate level degree | |
| 20. <input type="checkbox"/> Doctoral level degree | |
| 66. <input type="checkbox"/> Other | |

4. Did you earn a GED instead of graduating from high school? **geddis**

- | | |
|---|---|
| 1. <input type="checkbox"/> No | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Yes | 99. <input type="checkbox"/> Unknown |
| 77. <input type="checkbox"/> Not applicable | Variable added in 2015 |

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

- | | |
|---|---|
| 1. <input type="checkbox"/> I am not receiving disability income | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Social Security Disability | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Private long term insurance disability income | |
| 4. <input type="checkbox"/> Supplemental security income (SSI) | |
| 5. <input type="checkbox"/> Worker's compensation | |
| 6. <input type="checkbox"/> Other <u>disincdiso</u> | |

Variable names and information indicated in red. Numbers for response categories correspond to codes unless otherwise noted

6. Were you ever incarcerated for conviction of a felony? **feldis**

1. No

2. Yes **Variable added in 2015**

88. Declined to answer/Refused

99. Unknown

7. While in school, were you ever classified as a special education student? **speducdis**

1. No

2. Yes **Variable added in 2015**

88. Declined to answer/Refused

99. Unknown

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

1. No

2. Yes **Variable added in 2015**

88. Declined to answer/Refused

99. Unknown

Is there anything else you would like to tell us? _____

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

Indicate time survey ended: _____

Burn Model System Adult Form II Cover Sheet

To be administered at 6, 12, and 24 months and then every 5 years post-injury

This packet contains all forms to be used during all follow-up assessments of BMS longitudinal database participants.

These include:

1. Review of Systems Form II Checklist Form
2. Form II Adult Mail (without instructions to the interviewer/research staff, to be used when the participant fills out the survey themselves)
3. Form II Adult Interview (contains instructions to the interviewer/research staff, to be used when the research staff does the interview)
4. Form II Medical Record Abstraction Form

Instructions for Medical Record Abstraction Form:

There are certain items that are collected via medical record only at follow-up, if available. When filling out the medical record abstraction form, only use data from the medical record that is dated within the follow-up data collection window. Otherwise mark and enter the data coded as “99-Missing/unknown.”

Instructions for Mail Form II:

This form can be given to a participant in person if they are at the hospital for a follow-up visit, for them to fill out on their own time, or can be sent in the mail. After receiving the completed form in the mail or from a participant, go through the survey carefully to see if the participant missed any questions. If possible, call the participant or ask them in person the questions that were missed. If a participant doesn't want to answer any item or doesn't know the answer and there isn't a box/option for those responses on that item, write: “88” (Decline to Answer/Refused) or “99” (Unknown) next to the item. If items were left blank and it is not possible to recontact the participant, write “99” next to those items.

Instructions for Interview Form II:

Before administering Interview Form II for the first time, read through the survey and become comfortable with the interviewer instructions and skip patterns. There are prompts for difficult items and scripts to help provide information to participants. These may be used verbatim or adapted to fit the needs of each participant.

Date Medical Record Abstraction Form Collected: ____ / ____ / ____ mrafu_date

Instructions to BMS staff for use of this form: 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.

1. Follow-up period follow_up

1. 6-month follow-up
2. 12-month follow-up
3. 24-month follow-up
4. 5 year follow-up
5. 10 year follow-up
6. 15 year follow-up
7. 20 year follow-up
8. 25 year follow-up

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.

Previous variable was called "followup". For this new variable, additional time-points have been added. In the previous iteration, "followup", 4-Other.

Since the last follow-up, has the participant been diagnosed with...	Yes	No	Missing/ Unknown
1. Hypertension or high blood pressure? highbp_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
2. Congestive heart failure? conghf_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
3. Myocardial infarction or heart attack? heartatk_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
4. Heart arrhythmias? heartar_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
5. Stroke? stroke_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
6. Emphysema or asthma or COPD? copd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
7. High blood cholesterol? highchol_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
8. Diabetes, high blood sugar, or sugar in the urine? diab_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
9. Pneumonia? pneum_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
10. Liver disease (such as hepatitis)? hepat_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
11. Rheumatoid arthritis? rheum_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
12. Osteoarthritis? osteo_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
13. Sleep disorder like sleep apnea? sleepdis_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
14. Cataracts? catar_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
15. Chronic pain? chronpa_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
16. Dementia of some kind, like Alzheimer's? alzh_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
17. Parkinson's disease? parkd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
18. Alcoholism? etohadd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
19. Drug addiction? drugadd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
20. Depression? depress_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
21. Anxiety? anx_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
22. Panic attacks? panic_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
23. Bipolar disorder or manic-depression? bipol_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
24. Attention deficit disorder (ADD/attention deficit hyperactivity disorder (ADHD)? adhd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
25. Obsessive-compulsive disorder? ocd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
26. PTSD (post-traumatic stress disorder)? ptsd_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
27. Spinal cord injury? sci_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99
28. Traumatic brain injury? tbi_fu	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99

Burn Surgeries

Burn surgeries items moved to MRA form only in 2018

1. 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
 2. No
 99. Don't know

Note: data from surgery_fu and surgery_fuprx not imported into this new variable, to distinguish data collected from medical record versus self-report

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.

2. How many surgeries did the participant have? **numsurg** (added in 2015)
 (code 77 for N/A—no surgery and code 99 for unknown number of surgeries)

Data from numsurgprx moved to numsurg in 2018 when this was converted to medical record data abstraction

3. Which burn related surgeries has the participant had since the last follow-up? (Choose all that apply) **surgtype**

1. Surgery for open wounds
 2. Surgery for joint contractures
 3. Surgery for scar management (laser)
 4. Amputation
 5. Other (if so, what? **otrsurg** _____)
 77. Not applicable (no surgery)
 99. Missing/unknown

When data was converted in 2018, observations with a "no" for surgery_fu were coded as 77 in surgtype

When the data was converted to medical record abstraction only in 2018, proxy surgery data was moved into the surgtype data. Old variables, surgtype__1-surgtype__5 and surgtypeprx__1-surgtypeprx__5 were archived and can be accessed if needed.

Added in 2015 There are three other variables in the database, surgtype_2, surgtype_3, surgtype_4 that have the same coding in case more than one surgery is endorsed.

Amputations

Instructions: if the participant hasn't had surgery for amputation, fill in "no" for #4 and #5, below.

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

1. No **amputfu1__1**
 2. Yes, above elbow right **amputfu1__2** 0 = not checked
 3. Yes, above elbow left **amputfu1__3** 1 = checked
 4. Yes, above elbow bilateral **amputfu1__4**
 5. Yes, below elbow right **amputfu1__5**
 6. Yes, below elbow left **amputfu1__6**
 7. Yes, below elbow bilateral **amputfu1__7**
 8. Yes, digits only right **numudqtrfu** (fill in # of digits) **amputfu1__8**
 (Thumb amputated? **thumbrfu** 1 Yes 2 No)
 9. Yes, digits only left **numudqtlfu** (fill in # of digits) **amputfu1__9**
 (Thumb amputated? **thumblfu** 1 Yes 2 No)
 10. Yes, digits only bilateral (fill in # of digits) **amputfu1__10**
 (Thumbs amputated? **thumbbfu** 1 Yes 2 No)
 77. Not applicable (no amputations) **amputfu1__77**

Notes: New variable added with new Forms in 2015

2. Lower extremity amputation due to burn injury since last follow-up? (Choose all that apply)

1. No **amputfu2__1**
2. Yes, above knee right **amputfu2__2**
3. Yes, above knee left **amputfu2__3**
4. Yes, above knee bilateral **amputfu2__4**
5. Yes, below knee right **amputfu2__5**
6. Yes, below knee left **amputfu2__6**
7. Yes, below knee bilateral **amputfu2__7**
8. Yes, digits only right **_numldgtrfu** (fill in # of digits) **amputfu2__8**
9. Yes, digits only left **_numldgtlfu** (fill in # of digits) **amputfu2__9**
10. Yes, digits only bilateral **_numldgtbfu** (fill in # of digits) **amputfu2__10**
11. Transmetatarsal right (partial foot amputation right) **amputfu2__11**
12. Transmetatarsal left (partial foot amputation left) **amputfu2__12**
13. Transmetatarsal bilateral (partial foot amputation bilateral) **amputfu2__13**
77. Not applicable (no amputations) **amputfu2__77**

Notes:

New variable added with new Forms in 2015

Item with common pain medications added in July 2016 (check all that apply)Pain Medication Data Collection (only pain medication prescribed *within the data collection window* needs to be collected)

0. No pain medication **pmed_fup__0** 0 = not checked
1. Methadone **pmed_fup__1** 1 = checked
2. Codeine **pmed_fup__2**
3. Hydrocodon (Norco, Vicoden) **pmed_fup__3**
4. Oxycodone (Percodet, OxyContin) **pmed_fup__4**
5. Hydromorphone (Dilaudid) **pmed_fup__5**
6. Fentanyl (Duragesic) **pmed_fup__6**
7. Morphine **pmed_fup__7**
8. Acetaminophen with codeine (Tylenol #3) **pmed_fup__8**
9. Gabapentin (Neurontin) **pmed_fup__9**
10. Amitriptyline **pmed_fup__10**
99. Unknown **pmed_fup__11**

Pain Medication Table

Name of Pain Medication (prescribed in data collection window), if other than above
1. med1
2. med2
3. med3
4. med4
5. med5
6. med6
7. med7
8. med8
9. med9
10. med10
11. med11
12. med12

Today's Date: ____ / ____ / ____ **fup_date**

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: **fup_start_time**

Follow-up Information: *Interviewer instructions: Fill this page out before beginning the interview with the participant.*

1. Follow-up period **follow_up**

- 1. 6-month follow-up
- 2. 12 month follow-up
- 3. 24 month follow-up
- 4. 5 year follow-up
- 5. 10 year follow-up
- 6. 15 year follow-up
- 7. 20 year follow-up
- 8. Other: _____

Previous variable was called "followup". For this new variable, additional time-points have been added. In the previous iteration, "followup", 4-Other.

2. What is the method of administration of this form? **admin_fup**

- 1. In person
- 2. Mail
- 3. Telephone interview
- 4. Online
- 5. Medical record review

Previous variable was called "admin_2". For this new variable, additional options have been added—Online and Medical record review.

3. What is the language of administration of this form? **language_fup**

- 1. English
- 2. Spanish
- 3. Other

Previous variable was called "admin_2".

4. What is the status of this follow-up assessment? (Choose only one) **lostfolo**

- 1. Some or all assessment done
- 2. Death due to burn related complications
- 3. Death due to non-burn related complications
- 4. Unable to locate
- 5. Refused this assessment
- 6. Unable to test/med comp/incapable of responding
- 7. Failed to respond
- 8. Did not consent to future assessment/withdrew
- 11. Incarcerated
- 13. Still in hospital (not discharged yet)
- 14. Unable to travel for assessment

Interviewer Instructions: Update date and cause of death on Patient Status Form

Option 14 added with new forms in 2015

15. Death (unknown causes) (*Interviewer Instructions: Update date and cause of death on Patient Status Form*) **Option 15 added with new forms in 2018**

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. Have the updated Patient Status form with you to help with the interview.

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) next to that item.

Replace the introduction script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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 of individuals with burn injuries. Like our previous interviews, I'll be asking questions about your burn injury and other questions about you and people around you. 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."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Burn Injury Follow-up

Interviewer Instructions: throughout the survey, do not read section headings in Times New Roman font and italics aloud to participants.

First I have some questions related to your burn injury...

1. What is your primary mode of transportation? **transport**

- 1. Driving my own vehicle
- 2. Riding with someone else
- 3. Public transit
- 77. Not applicable (I don't use motorized transport)
- 88. Declined to answer/Refused
- 99. Unknown

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 interview, have you spoken with other burn survivors to get support for problems related to your burn injury? **peersup**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

Added in 2015

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

If clarification needed: 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.

- 1. No services **services__1** (*Interviewer Instructions: skip to #7, surgery item, on page 4*)
- 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**
- 88. Declined to answer/Refused **services__88**
- 99. Unknown **services__99**

0 = not checked
1 = checked

Added in 2015

Interviewer Instructions: if participant indicates that services were received but that those services were not occupational and/or physical therapy, skip to #7, surgery item, on page 4.

Interviewer Instructions: Continue with these questions if the participant received OT and/or PT...

4. How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? **numther**

- 1. One
- 2. 2-4
- 3. 5-10
- 4. More than 10
- 77. No PT/OT (*skip to #7, surgery item, on page 4*)
- 88. Declined to answer/Refused
- 99. Unknown

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.

Since your last interview, where did you receive your outpatient occupational or physical burn therapy?

- 5 Burn center? **ther_brn_cntr**
1. Yes
 2. No
 77. Not applicable (no OT/PT received)
88. Declined to answer/Refused
 99. Unknown

New coding for 77/88/99 added in 2015

6. Other facility? **ther_otr**
1. Yes
 2. No
 77. Not applicable (no OT/PT received)
88. Declined to answer/Refused
 99. Unknown

New coding for 77/88/99 added in 2015

7. Since your last interview [*provide date*], have you had any burn related surgeries (such as surgeries for open wounds or scar management)? **surgery_fu**
1. Yes
 2. No (*Interviewer Instructions: skip to Review of Systems, below*)
 99. Don't know (*Interviewer Instructions: skip to Review of Systems, below*)
88. Declined to answer/Refused

Notes:

Parentetical statement (such as surgeries for open wounds or scar management) added to variable with new Forms in 2018

Interviewer Instructions: Continue with this question if the participant had burn related surgeries

8. Have you had any burn-related surgeries outside of [*name the BMS center*]? **surgout**
1. Yes
 2. No
88. Declined to answer/Refused
 99. Unknown

Added in 2015

Review of Systems:

(Interviewer Instructions: Skip to the next section (Pain Medication on page 5) if the participant has already filled out the Review of Systems for this data collection time-point.

For all ROS items, 1=Yes, 2=No, 88=Declined to answer/Refused, 99=Missing/unknown

Please answer each question as it relates to your <u>current</u> health:				
1. Hearing loss? hloss	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
2. Change in voice? voice	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
3. Vision problems not corrected by glasses or contact lenses? vision	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
4. Eyelid problems? eyelid	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
5. Excessive tearing of the eyes? tear	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
6. Difficulty with memory? memory	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
7. Difficulty with thought processing? thought	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
8. Numbness, pins and needles or burning sensations in your burn scar? numbsc	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
9. Numbness, pins and needles or burning sensations in your hands? numbh	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
10. Numbness, pins and needles or burning sensations in your feet? numbf	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
11. Trouble with your balance? tbalan	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused

12. Varicose veins? varvein	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
13. Swollen feet or legs? swfleg	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
14. Swollen hands or arms? swharm difbrereg	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
15. Difficulty breathing when doing your regular daily activities?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
16. Skin cancer? skincanc	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
17. Joint pain? jpain	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
18. Have you been pregnant or fathered a child since your last interview? preg_fath	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
19. Blood clots in legs or lungs? bceglung	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
20. Cold intolerance? cintol	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
21. Excessive sweating? exsweat	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
22. Difficulty in hot environments? difhot	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused
23. Is your skin more sensitive than before your burn? skinsens	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	88/Refused

Pain Medication

1. In the **past month** did you take prescription medication for pain on a regular basis? **pmed**

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

2. In the **past month** did you take prescription medication for itch on a regular basis? **imed**

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

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

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

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

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

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

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

4-D Itch scale:

These next questions are about itching in the past two weeks.

During the last two weeks, have you had any itching in the area of your burn, skin grafts, or donor sites? **itchscr**

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown
(Interviewer instructions: skip to the VRI2 section on page 7)

1. During the last two weeks, how many hours a day have you been itching? **itch1**

- 1. Less than 6 hours a day
- 2. 6-12 hours a day
- 3. 12-18 hours a day
- 4. 18-23 hours a day
- 5. All day
- 77. Not applicable (no itching)
- 88. Declined to answer/Refused
- 99. Unknown

2. Please rate the intensity of your itching over the past two weeks: **itch2**

- 1. Not present
- 2. Mild
- 3. Moderate
- 4. Severe
- 5. Unbearable
- 77. Not applicable (no itching)
- 88. Declined to answer/Refused
- 99. Unknown

3. Over the past two weeks, has your itching gotten better or worse compared to the previous month? **itch3**

- 1. Completely resolved
- 2. Much better, but still present
- 3. Little bit better, but still present
- 4. Unchanged
- 5. Getting worse
- 77. Not applicable (no itching)
- 88. Declined to answer/Refused
- 99. Unknown

4. Please rate the impact of your itching on the following activities in the past two weeks:

	Not applicable	Never affects sleep	Occasional ly delays falling asleep	Frequently delays falling asleep	Delays falling asleep and occasionally wakes me up at night	Delays falling asleep and frequently wakes me up at night
Sleep itch4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

88 / 99

	Not applicable	Never affects this activity	Rarely affects this activity	Occasionally affects this activity	Frequently affects this activity	Always affects this activity
Leisure/social: itch5	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Housework/errands: itch6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work/school: itch7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88 / 99

88 / 99

88 / 99

4-D Itch Total Scores:

- itch_dur:** Itch Duration Score
- itch_deg:** Itch Degree Score
- itch_dir:** Itch Direction Score
- itch_dis:** Itch Disability Score
- itch_tot:** Itch Total Score

Interviewer Instructions: Reminder: participants can skip any questions they do not want to answer. If they indicate that they don't want to answer any VR12 question, let them skip it and move on to the next item. If they do not want to answer an item, circle "88/Refused" next that item on the Form and move on. If a response is missing, circle "99/Unknown" next to that question.

VR-12:

INSTRUCTIONS: The next questions ask you for your views about your health. This information will keep track of how you feel and how well you are able to do your usual activities. Answer every question by choosing a response. If you are unsure how to answer a question, please give your answer the best you can.

Interviewer Instructions: Circle one number on each line

1. In general, would you say your health is: **vr12_1**

EXCELLENT	VERY GOOD	GOOD	FAIR	POOR	
1	2	3	4	5	88/Refused 99/Unknown

Look at your Answer Key on page 1, Section 2, Option B.

2. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? **vr12_2a**

YES,
LIMITED
A LOT YES,
LIMITED
A LITTLE NO,
NOT
LIMITED
AT ALL

1 2 3 88/Refused
99/Unknown

b. Climbing **several** flights of stairs? **vr12_2b**

1 2 3 88/Refused
99/Unknown

3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?**

a. **Accomplished less** than you would like. **vr12_3a**

NO,
NONE
OF THE
TIME YES,
A LITTLE
OF THE
TIME YES,
SOME
OF THE
TIME YES,
MOST
OF THE
TIME YES,
ALL
OF THE
TIME

1 2 3 4 5 88/Refused
99/Unknown

b. Were limited in the **kind** of work or other activities. **vr12_3b**

1 2 3 4 5 88/Refused
99/Unknown

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

a. **Accomplished less** than you would like. **vr12_4a**

NO,
NONE
OF THE
TIME YES,
A LITTLE
OF THE
TIME YES,
SOME
OF THE
TIME YES,
MOST
OF THE
TIME YES,
ALL
OF THE
TIME

1 2 3 4 5 88/Refused
99/Unknown

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	NO, NONE OF THE TIME	YES, A LITTLE OF THE TIME	YES, SOME OF THE TIME	YES, MOST OF THE TIME	YES, ALL OF THE TIME	
b. Didn't do work or other activities as carefully as usual. vr12_4b	1	2	3	4	5	88/Refused 99/Unknown

5. During the past 4 weeks, how much did **pain** interfere with your normal work (including both work outside the home and house work)? **vr12_5**

NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	2	3	4	5	88/Refused 99/Unknown

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

6. How much of the time during the past 4 weeks:

	ALL OF THE TIME	MOST OF THE TIME	A GOOD BIT OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME	
a. Have you felt calm and peaceful ? vr12_6a	1	2	3	4	5	6	88/Refused 99/Unknown
b. Did you have a lot of energy ? vr12_6b	1	2	3	4	5	6	88/Refused 99/Unknown
c. Have you felt downhearted and blue ? vr12_6c	1	2	3	4	5	6	88/Refused 99/Unknown

7. During the past 4 weeks, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)? **vr12_7**

ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME	
1	2	3	4	5	88/Refused 99/Unknown

Modified PROMIS Profile 29:

Next I have several questions about things like how well you are able to do physical activities, and about things like depression, sleep, and pain.

Please respond to each question or statement by choosing a response.

PHYSICAL FUNCTION

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do	
1. Are you able to do chores such as vacuuming or yard work? pfa11	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	88/Refused 99/Unknown
2. Are you able to go up and down stairs at a normal pace? pfa21	<input type="checkbox"/>	88/Refused 99/Unknown				
3. Are you able to go for a walk of at least 15 minutes? pfa23	<input type="checkbox"/>	88/Refused 99/Unknown				
4. Are you able to run errands and shop? pfa53	<input type="checkbox"/>	88/Refused 99/Unknown				

PROMIS Physical Function T-Score: pftscore

ANXIETY

In the past 7 days...	Never	Rarely	Sometimes	Often	Always	
5. I felt fearful edanx01	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
6. I found it hard to focus on anything other than my anxiety edanx40	<input type="checkbox"/>	88/Refused 99/Unknown				
7. My worries overwhelmed me edanx41	<input type="checkbox"/>	88/Refused 99/Unknown				
8. I felt uneasy edanx53	<input type="checkbox"/>	88/Refused 88/Refused 99/Unknown				
9. I felt nervous edanx465	<input type="checkbox"/>	88/Refused 99/Unknown				
10. I felt like I needed help for my anxiety edanx076	<input type="checkbox"/>	88/Refused 99/Unknown				

Variables edanx465 and edanx076 added in 2018

PROMIS Anxiety T-Score: anxtscore

DEPRESSION

In the past 7 days...		Never	Rarely	Sometimes	Often	Always	
11.	I felt worthless eddep04	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
12.	I felt helpless eddep06	<input type="checkbox"/>	88/Refused 99/Unknown				
13.	I felt depressed eddep29	<input type="checkbox"/>	88/Refused 99/Unknown				
14.	I felt hopeless eddep41	<input type="checkbox"/>	88/Refused 99/Unknown				
15.	I felt like a failure eddep225	<input type="checkbox"/>	88/Refused 99/Unknown				
16.	I felt unhappy eddep366	<input type="checkbox"/>	88/Refused 99/Unknown				

Variables **eddep225** and **eddep366** added in 2018

PROMIS Depression T-Score: **deptscore**

FATIGUE

During the past 7 days...		Not at all	A little bit	Somewhat	Quite a bit	Very much	
17.	I feel fatigued hi7	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
18.	I have trouble <u>starting</u> things because I am tired an3	<input type="checkbox"/>	88/Refused 99/Unknown				
In the past 7 days...							
19.	How run-down did you feel on average? fatexp41	<input type="checkbox"/>	88/Refused 99/Unknown				
20.	How fatigued were you on average? fatexp40	<input type="checkbox"/>	88/Refused 99/Unknown				

PROMIS Fatigue T-Score: **fatscore**

SLEEP DISTURBANCE

In the past 7 days...		Very poor	Poor	Fair	Good	Very good	
21.	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	88/Refused 99/Unknown
In the past 7 days...		Not at all	A little bit	Somewhat	Quite a bit	Very much	
22.	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	88/Refused 99/Unknown
23.	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	88/Refused 99/Unknown
24.	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	88/Refused 99/Unknown

PROMIS Sleep Disturbance T-Score: **sleeptscore**

ABILITY TO PARTICIPATE IN SOCIAL ROLES AND ACTIVITIES

	Never	Rarely	Sometimes	Usually	Always	
25. I have trouble doing all of my regular 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	88/Refused 99/Unknown
26. I have trouble keeping up with my family responsibilities srpper22	<input type="checkbox"/>	88/Refused 99/Unknown				
27. I have trouble doing all of my usual work (include work at home) srpper23	<input type="checkbox"/>	88/Refused 99/Unknown				
28. I have trouble keeping in touch with others srpper43r1	<input type="checkbox"/>	88/Refused 99/Unknown				

PROMIS Ability to Participate in Social Roles T-Score: **socroltscore**

PAIN INTERFERENCE

In the past 7 days...	Not at all	A little bit	Some-what	Quite a bit	Very much	
29. How much did pain interfere with your day to day activities? painin9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	88/Refused 99/Unknown
30. How much did pain interfere with work around the home? painin22	<input type="checkbox"/>	88/Refused 99/Unknown				
31. How much did pain interfere with your ability to participate in social activities? painin31	<input type="checkbox"/>	88/Refused 99/Unknown				
32. How much did pain interfere with your household chores? painin34	<input type="checkbox"/>	88/Refused 99/Unknown				

PROMIS Pain Interference T-Score: **painintscore**

Pain Intensity

	No pain					Worst imaginable pain						
In the past 7 days...	0	1	2	3	4	5	6	7	8	9	10	
33. How would you rate your pain on average? global07	<input type="checkbox"/>	88/Refused 99/Unknown										

Sexual Function & Satisfaction

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

Sexual Function & Satisfaction added in 2018

Upper Extremity PROMIS Sexual FS T-Score: **sfsattscore**

Interviewer Instructions: If the participant had a hand burn, please complete the next 4 questions. If the participant did NOT have a hand burn, please move on to NeuroQOL Stigma SF, below

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do	
1. Are you able to cut your food using eating utensils? pfa20	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	88/Refused 99/Unknown
2. 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	88/Refused 99/Unknown
3. 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	88/Refused 99/Unknown
4. 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	88/Refused 99/Unknown

Upper extremity sections added in 2018

NeuroQOL Stigma Short Form:

PROMIS Upper Extremity T-Score: upextscore

Next I have some questions about some things you may have experienced due to your injury.

Please respond to each question or statement by choosing one response.

Lately...	Never=1	Rarely=2	Sometimes=3	Often=4	Always=5	
1. Because of my injury, some people avoided me. nqstg02	<input type="checkbox"/>	88/Refused 99/Unknown				
2. Because of my injury, I felt left out of things. nqstg04	<input type="checkbox"/>	88/Refused 99/Unknown				
3. Because of my injury, people avoided looking at me. nqstg08	<input type="checkbox"/>	88/Refused 99/Unknown				
4. I felt embarrassed about my injury. nqstg16	<input type="checkbox"/>	88/Refused 99/Unknown				
5. Because of my injury, some people seemed uncomfortable with me. nqstg01	<input type="checkbox"/>	88/Refused 99/Unknown				
6. I felt embarrassed because of my physical limitations. nqstg17	<input type="checkbox"/>	88/Refused 99/Unknown				
7. Because of my injury, people were unkind to me. nqstg05	<input type="checkbox"/>	88/Refused 99/Unknown				
8. Some people acted as though it was my fault I have this injury. nqstg21	<input type="checkbox"/>	88/Refused 99/Unknown				

NeuroQOL Stigma SF T-Score: nqstgtscore

Burn Specific Health Body Image Sub-Scale:

Below is a list of problems, complaints and feelings that people sometimes have following a burn injury. I will read each one carefully and ask you to select the response that best describes your experience. Please do not skip any items, and ask for help if you have questions or difficulties with any of the items.

To what extent does each of the following statements describe you?	Extreme(ly) =0	Quite a bit =1	Moderate(ly) =2	A little bit =3	None (not at all) =4	
BH24. Sometimes, I would like to forget that my appearance has changed. bshs_24	<input type="checkbox"/>	88 / 99				
BH25. I feel that my burn is unattractive to others. bshs_25	<input type="checkbox"/>	88 / 99				
BH26. My general appearance really bothers me. bshs_26	<input type="checkbox"/>	88 / 99				
BH27. The appearance of my scars bothers me. bshs_27	<input type="checkbox"/>	88 / 99				

Burn Specific Health Scale replaced with Burn Specific Health Body Image Sub-Scale in 2018

BSHS Body Image: bshs_bi

CAGE Alcohol Use:

Now I have a few questions about alcohol and drugs.

Interviewer instructions: If the participant states they do not drink after the first question, you can fill in “No” for all four questions and skip to CAGE Drug Use, on the next page.

In the past year...(Or, since your last interview, if this is the 6 or 12 month interview)

1. Have you felt you needed to **C**ut down on your drinking? Yes (1) No (0)
2. Have people **A**nnoyed you by criticizing your drinking? Yes (1) No (0)
3. Have you ever felt **G**uilty about drinking? Yes (1) No (0)
4. Have you ever felt you needed a drink first thing in the morning (**E**ye-opener) to steady your nerves or to get rid of a hangover? Yes (1) No (0)

CAGE Drug use:

Interviewer instructions: If clarification is needed, say, “We are wanting to know about 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.”

Interviewer instructions: If the participant states they do not drink after the first question, you can fill in “No” for all four questions and skip to PTSD Checklist, below.

In the past year...(Or, since your last interview, if this is the 6 or 12 month interview)

1. Have you ever felt you needed to **Cut** down on your drug use? Yes (1) No (0)
2. Have people **Annoyed** you by criticizing your drug use? Yes (1) No (0)
3. Have you ever felt **Guilty** about your drug use? Yes (1) No (0)
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? Yes (1) No (0)

Interviewer instructions: Do not ask the following questions, but fill in by summing the responses (total number of “yes” responses), above.

Patient’s history of alcohol abuse in the past year (or since last interview): **etohabufup**

1. Yes (C-A-G-E=2,3,4) 88. Declined to answer/Refused
2. No (C-A-G-E=0,1) 99. Unknown

Patient’s history of drug abuse the past year (or since last interview): **drugabufup**

1. Yes (C-A-G-E=2,3,4) 88. Declined to answer/Refused
2. No (C-A-G-E=0,1) 99. Unknown

PTSD Checklist:

Now I will read a list of problems and complaints that people sometimes have in response to stressful life experiences like burn injuries. Please choose a response that indicates how much you have been bothered by that problem in the last month.

How much have you been bothered by...	Not at all (1)	A little bit (2)	Moderately (3)	Quite a bit (4)	Extremely (5)	
1. Repeated, disturbing <i>memories, thoughts, or images</i> of your burn injury? pclc_1	<input type="checkbox"/>	88 / 99				
2. Repeated, disturbing <i>dreams</i> of your burn injury? pclc_2	<input type="checkbox"/>	88 / 99				
How much have you been bothered by...	Not at all (1)	A little bit (2)	Moderately (3)	Quite a bit (4)	Extremely (5)	
3. Suddenly <i>acting or feeling</i> as if your burn injury were happening again (as if you were reliving it)? pclc_3	<input type="checkbox"/>	88 / 99				

4. Feeling <i>very upset</i> when <i>something</i> reminded you of your burn injury? pclc_4	<input type="checkbox"/>	88 / 99				
5. Having <i>physical reactions</i> (e.g., heart pounding, trouble breathing, or sweating) when <i>something</i> reminded you of your burn injury? pclc_5	<input type="checkbox"/>	88 / 99				
6. Avoid <i>thinking about</i> or <i>talking about</i> your burn injury or avoid <i>having feelings</i> related to it? pclc_6	<input type="checkbox"/>	88 / 99				
7. Avoid <i>activities</i> or <i>situations</i> because they <i>remind you</i> of your burn injury? pclc_7	<input type="checkbox"/>	88 / 99				
8. Trouble <i>remembering important</i> parts of your burn injury? pclc_8	<input type="checkbox"/>	88 / 99				
9. Loss of <i>interest in things that you used to enjoy</i> ? pclc_9	<input type="checkbox"/>	88 / 99				
10. Feeling <i>distant</i> or <i>cut off</i> from other people? pclc_10	<input type="checkbox"/>	88 / 99				
11. Feeling <i>emotionally numb</i> or being unable to have loving feelings for those close to you? pclc_11	<input type="checkbox"/>	88 / 99				
12. Feeling as if your <i>future</i> will somehow be <i>cut short</i> ? pclc_12	<input type="checkbox"/>	88 / 99				
13. Trouble <i>falling</i> or <i>staying asleep</i> ? pclc_13	<input type="checkbox"/>	88 / 99				
14. Feeling <i>irritable</i> or having <i>angry outbursts</i> ? pclc_14	<input type="checkbox"/>	88 / 99				
15. Having <i>difficulty concentrating</i> ? pclc_15	<input type="checkbox"/>	88 / 99				
16. Being " <i>super alert</i> " or watchful on guard? pclc_16	<input type="checkbox"/>	88 / 99				
17. Feeling <i>jumpy</i> or easily startled? pclc_17	<input type="checkbox"/>	88 / 99				

PCLC Total Score Variable: **ptsdc_tot**
PCLC DSM Criteria Score Variable: **ptsdc_dsm**

CIO:

The next questions I have are about some activities you might have participated in recently.

Currently:

- 1: Who usually looks after your personal finances, such as banking and paying bills? **cia2**
- 1. Yourself alone
 - 2. Yourself and someone else
 - 3. Someone else
 - 88. Declined to answer/Refused
 - 99. Unknown

Approximately how many times a month do you usually participate in the following activities outside of your home?

- 2: Shopping **ci3**
- 1. Never
 - 2. 1-4 times
 - 3. 5 or more times
 - 88. Declined to answer/Refused
 - 99. Unknown

3: Leisure activities such as movies, sports, and restaurants. **ci4**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times
- 88. Declined to answer/Refused
- 99. Unknown

4: Visiting friends or relatives **ci5**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times
- 88. Declined to answer/Refused
- 99. Unknown

5: When you participate in leisure activities do you usually do this alone or with others? **ci6**

- 1. Mostly alone
- 2. Mostly with friends who have burn injuries
- 3. Mostly with family members
- 4. Mostly with friends who do not have burn injuries
- 5. With a combination of family and friends
- 77. Not applicable (no leisure activities)
- 88. Declined to answer/Refused
- 99. Unknown

6: Do you have a best friend with whom you confide? **ci7**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

CIQ Social Integration Total Score: ciqsic

Satisfaction with Life:

Here are 5 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. 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: sl1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. The conditions of my life are excellent: sl2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I am satisfied with my life sl3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. So far, I have gotten the important things I want in life sl4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. If I could live my life over again I would change almost nothing: sl5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

Satisfaction with Life Total Score: swlscore

PTGI:

Next 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

Question	0=I did not experience this change	1=To a very small degree	2=To a small degree	3=To a moderate degree	4=To a great degree	5=To a very great degree	
1. I changed my priorities about what is important in life ptgi_1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I have a greater appreciation for the value of my own life ptgi_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I am able to do better things with my life. ptgi_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I have a better understanding of spiritual matters. ptgi_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. I have a greater sense of closeness with others. ptgi_5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. I established a new path for my life. ptgi_6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. I know better that I can handle difficulties. ptgi_7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. I have a stronger religious faith. ptgi_8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. I've discovered that I'm stronger than I thought I was. ptgi_9	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. I learned a great deal about how wonderful people are. ptgi_10	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

Post Traumatic Growth Inventory Total Score: **ptgitot**

DEMOGRAPHICS:

Next I have some general questions about you. This is the last section of the survey.

Interviewer instructions: Record participant's weight and height in pounds and feet/inches but enter into the database in kg and cm.

1. What is your current weight? (lbs) htfu (code 9999 for unknown)

Added to adult data collection in 2015

2. What is your current height? (feet/inches) wtfu (code 9999 for unknown)

Added to adult data collection in 2015

3. Where are you currently living? (Choose only one) resdenclu

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

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.

4. What is your current zip code? zipfu

(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

5. Who are you currently living with? (Choose all that apply)

Interviewer instructions: Probe if needed to make sure that all people participant is living with are accounted for in their answer.

- 1. Alone livingafu__1
- 2. Spouse/partner/significant other livingafu__2
- 3. Friend livingafu__3
- 4. Parent or step-parent livingafu__4
- 5. Other relative (siblings, grandparents) livingafu__5
- 6. Others, not part of family livingafu__6
- 7. Guardian livingafu__7
- 8. Young children livingafu__8
- 9. Adult children livingafu__9
- 88. Declined to answer/Refused livingafu__88
- 99. Unknown livingafu__99

6. What is your current marital status? (Choose only one) marstatfu

- 1. Married; living common-law or with a partner
- 2. Separated
- 3. Divorced
- 4. Widowed
- 5. Single (not married)
- 99. Unknown
- 88. Declined to answer/Refused
- 99. Unknown

7. Approximately what was your household's total income for the last full year (total income of all members of the household)?

If clarification is needed about the reason this question is asked, say, "Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds."

*If clarification about currency is needed, say, "these categories are in U.S. dollar amounts." **hinccatfup***

- | | |
|--|---|
| 1. <input type="checkbox"/> Less than \$25,000 | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> \$25,000-\$49,999 | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> \$50,000-\$99,999 | |
| 4. <input type="checkbox"/> \$100,000-\$149,999 | |
| 5. <input type="checkbox"/> \$150,000-\$199,999 | |
| 6. <input type="checkbox"/> \$200,000 or more | |
| 7. <input type="checkbox"/> Living outside the United States | |
| 77. <input type="checkbox"/> Not applicable (e.g., living in an institution) | |

8. How many people are in your household? **numhsfup**

(Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

9. In the past year, how many months did you work at a regular job? **mrjobfup** *(fill in # of months)*
(Interviewer Prompt: If necessary, say, "This would include any job for which you were paid at least minimum wage, and worked without the help of another person like a job coach or therapist")

0. Less than 1 month
77. Not applicable (did not work in the past year)
88. Declined to answer/Refused
99. Unknown

10. What is your primary occupation? *(Or, if worked less than 1 month in the past year...The last time you worked, what was your primary occupation?)*

Occupation: **occfup**_____

Code: **occodefup**_____

Interviewer instructions: Ask this as an open-ended question. Fill out the blank with the occupation the participant states and then the code, found below.

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; 77 – Not Applicable; 88 – Declined to Answer/Refused; 99 – Unknown

11. What is your current employment status? (Choose only one) **employ_fup**

- 1. Working (*Interviewer Instructions: continue with next question*)
 - 2. Not working (looking for work)
 - 3. Not working (not looking for work)
 - 4. Homemaker/caregiver
 - 5. Volunteer
 - 6. Retired
 - 99. Unknown
- *Interviewer Instructions: skip to #15, below*

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”.**

12. 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.
- 88. Declined to answer/Refused
- 99. Unknown

New variable added in 2018

Interviewer instructions: Skip #13 and move on to #14 if this is a 5, 10, 15, etc year follow-up interview or if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.

13. What was your first date to return to work/school since injury?: ____/____/____

Entered into the patient status form: returndat

14. About how many hours a week do you work for pay? **hpayfup**_____

- 777. Not applicable (not employed)
- 888. Declined to answer/Refused
- 999. Unknown

Interviewer Instructions: Skip#15 and move on to #16 on the next page 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).

15. Approximately what was your individual income for the past full year? **iinccatfup**

If clarification about currency is needed, say, “these categories are in U.S. dollar amounts.”

- 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. Declined to answer/Refused
- 99. Unknown

16. What is your current school status? **aschoolfu**

- 1. In School (*Interviewer Instructions: Continue with #17 below if this is a 6, 12, or 24 month follow-up. Skip to #18 if this is a 5, 10, or 15 year follow-up.*)
- 2. Not in School (*Interviewer Instructions: Skip to #18, below*)
- 99. Unknown

Interviewer Instructions: If in school and this is a 6, 12, Or 24 month follow-up, ask...

17. ...is it the same program or a new program as compared with your last interview? (Or, as compared with before your burn injury, if this is a 6 month follow-up). **aprogrfu**

Interviewer Instructions: Ask as open ended question and probe about part or full time school status.

- 1. Same program full time
- 2. Same program part time
- 3. New program full time
- 4. New program part time
- 5. Did not resume school
- 6. Returned to individual program, home school
- 7. Not in school
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer Instructions: Skip to #19 on the next page if the participant is going to work or school.

18. If you aren't working or going to school, why not? **whynotfu**

- 1. Burn related
- 2. Other medical problems
- 3. Problems with employer
- 4. Emotional/social
- 5. Legal/jail
- 6. Substance abuse
- 7. Personal choice
- 8. Other
- 9. Retired
- 10. Homemaker/caregiver
- 11. Unemployed but actively seeking employment
- 77. Not applicable (working or going to school)
- 88. Declined to answer/Refused
- 99. Unknown

19. How many years of education have you completed?

(Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, "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.") If participant tries to count years rather than degree attained, use the prompt, "In other words, what is the highest level of education you have completed?". educfup

Interviewer Instructions: Ask the question as open-ended, and then mark the appropriate response below.

- 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
- 13. Work towards Associate's degree, vocational degree, or trade school diploma/certificate
- 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. Declined to answer/Refused
- 99. Unknown

Interviewer Instructions: Skip to #21 below if the participant has a high school diploma or if they have already answered "yes" to the GED item in a previous interview.

20. Did you earn a GED instead of graduating from high school? gedfup

- 1. No
- 2. Yes
- 77. Not applicable
- 88. Declined to answer/Refused
- 99. Unknown

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

- 1. I am not receiving disability income (*Interviewer Instructions: skip to #23 on the next page if the participant is not receiving disability income*)
- 2. Social Security Disability
- 3. Private long term insurance disability income
- 4. Supplemental security income (SSI)
- 5. Worker's compensation
- 6. Other disincfupo
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer Instructions: If the participant is receiving disability income, continue with #22

22. 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. Unknown

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

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

24. Do you currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimpfup**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

25. Who is the primary sponsor of your care currently, or who is paying for the majority of your burn care costs? (Choose only one) **pay_fup**

- 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)
- 88. Declined to answer/Refused
- 99. Unknown

*Notes: 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.*

26. Were you ever incarcerated for conviction of a felony? **felfup**

- 1. No
- 2. Yes
- 88. Declined to answer/Refused
- 99. Unknown

27. Have you ever served in the military? **milfup**

- 1. No
- 2. Yes
- 88. Declined to answer/Refused
- 99. Unknown

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!"

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____ **disdcddate**
(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: start_time

1. What is the method of administration of this form? **admin**
 1. In person
 2. Mail
 3. Telephone interview
 4. Online
 5. Medical record review

2. What is the language of administration of this form? **language**
 1. English
 2. Spanish
 3. Other

3. Checklist of forms: mark when each is complete **status**
 1. Patient Status Form **status__1**
 2. Medical Record Abstraction Form **status__2**
 3. Form I **status__3**

Interviewer Instructions: *Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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.*

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) next to that item.

Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Child Health Conditions

Interviewer instructions: Each question below is answered "yes" or "no".

If answered "yes", then ask "To what extent does this problem affect your daily activities?"

Responses for this question are:

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>
------------------------	------------------------------------	-------------------------------	----------------------------------	--------------------------------------	-------------------------------	------------------------------------

First, I'd like to ask some questions about your current health and medical condition. For any conditions that you have, I'll ask you to what extent the condition affects your daily activities.

Do you have problems...	Problem?	1	2	3	4	5	6	7	
1. Seeing? chcself1, chcself1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
2. Hearing? chcself2, chcself2a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
3. Learning and understanding? chcself3, chcself3a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcself4, chcself4a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
5. Controlling emotions or behavior? chcself5, chcself5a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
6. with Seizures or epilepsy? chcself6, chcself6a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcself7, chcself7a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
8. with Teeth and gums? chcself8, chcself8a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
10. with Type 1 or Type 2 diabetes? chcself10, chcself10a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
11. with Growth? chcself12, chcself12a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
12. Sleeping? chcself13, chcself13a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
13. with Repeated infections? chcself14, chcself1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
14. with Breathing (eg asthma)? chcself1, chcself14a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
15. with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
16. with other Skin problems (eg eczema)? chcself16, chcself16a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
17. with the Heart (such as a birth defect)? chcself17, chcself17a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
18. with Pain? chcself18, chcself18a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						

19. Do you have any other health problems? 1 Yes 0 No 88. Declined to answer/Refused
99. Unknown
chcself19

If yes, specify problem: _____

Pre-Injury History

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.

NIH TB General Life Satisfaction CAT Ages 13-17

Indicate how much you agree or disagree...

In the four weeks before my burn...	Strongly Disagree=1	Disagree=2	Neither Agree nor Disagree=3	Agree=4	Strongly Agree=5	
1. My life was going well. pa066pre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My life was just right pa067pre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I had a good life pa070pre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I had what I wanted in life pa071pre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

NIH General Life Satisfaction Total Score Pre-Injury: tbglstscore_13_17_pre

CIO Pre-Burn:

The next questions I have are about activities you might have participated in before your burn injury.

During the 4 weeks before your burn:

1. Did you take responsibility for personal grooming when asked? cip2_pre
1. Often 88. Declined to answer/Refused
 2. Sometimes 99. Unknown
 3. Never

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 88. Declined to answer/Refused
 2. 1-4 times 99. Unknown
 3. 5 or more times

3. Leisure activities such as movies, sports, and restaurants. ci4_pre
1. Never 88. Declined to answer/Refused
 2. 1-4 times 99. Unknown
 3. 5 or more times

4. Visiting friends or relatives **ci5_pre**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times
- 88. Declined to answer/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?

ci6_pre

- 1. Mostly alone
- 3. Mostly with family members
- 4. Mostly with friends
- 5. With a combination of family and friends
- 77. Not applicable (no leisure activities)
- 88. Declined to answer/Refused
- 99. Unknown

6. Did you have a best friend with whom you confided? **ci7_pre**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

CIQ Social Integration Subscale Total Score Pre-Injury: ciqsic_pre

Pain Medication

1. In the month before your burn injury did you take prescription medication for pain on a regular basis? **pmed_pre**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

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

wmed_pre

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

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

smed_pre

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

4. Did you receive psychological therapy or counseling in the last 12 months? **psychtr**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

Pre-Injury Demographics

1. Before your burn injury, where were you living? (Choose only one) **resdenc**
- 1. Private residence
 - 2. Nursing home
 - 4. Correctional institution
 - 5. Hotel/motel
 - 6. Homeless
 - 7. Hospital
- 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? ___ ___ ___ ___ ___ **zip_pre**
(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

Added to data collection forms in 2015.

3. Who were you living with before your burn injury? (Choose all that apply)
- 4. Parent or step-parent **livinga___4**
 - 5. Other relative (siblings, grandparents) **livinga___5**
 - 6. Others, not part of family **livinga___6** 0 = not checked
 - 7. Guardian **livinga___7** 1 = checked
 - 88. Declined to answer/Refused
 - 99. Unknown

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn injury?". Also changed variable so that multiple answers were acceptable.

4. Were you enrolled in school at the time of your burn injury? (If yes) Are you ahead, at the same level, or behind what grade you should be in for your age group? **school**
- 1. In school/age or above age appropriate
 - 2. Not in school
 - 3. In school/below age appropriate
 - 88. Declined to answer/Refused
 - 99. Unknown

Interviewer instructions: Skip to #6, below, if participant was going to school before the burn injury.

5. If you were not enrolled in school at the time of your burn injury, why not? **whynot**
- 2. Other medical problems
 - 4. Emotional/social
 - 5. Legal/jail
 - 6. Substance abuse
 - 7. Personal choice
 - 8. Other
 - 88. Declined to answer/Refused
 - 99. Unknown

6. Before your burn injury, did you have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? **physprobpre** (this variable replaced "physdis" in 2015)
- 1. Yes
 - 2. No
 - 88. Declined to answer/Refused
 - 99. Unknown

7. Before your burn injury, did you have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimppre**
- 1. Yes

- 2. No
- 99. Don't know

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)?

- 1. Depression psychlist
- 2. Bipolar disorder 0=No
- 3. Anxiety
- 4. Post-Traumatic Stress Disorder (PTSD)
- 5. Schizophrenia/psychotic disorder
- 6. Other, please explain: psychlistot

- 88. Declined to answer/Refused
- 99. Unknown

There are two other variables in the database, *psychlist2* and *psychlist3*, that have the same coding in case more than one issue is endorsed.

All the questions you just answered were about the time before your burn injury. Next are some questions about you and your burn injury.

Pain

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

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

Demographics

This is the last section of the survey.

Interviewer Instructions: Use medical record for #1-3. Skip these questions unless self-report is best source, and record answer onto the Form I Medical Record Abstraction Form along with source of data.

- 1. What is your racial group? race
 - 1. Black or African-American
 - 2. Asian
 - 3. Caucasian (white)
 - 4. American Indian/Alaskan Native
 - 5. Native Hawaiian or Other Pacific Islander
 - 6. More than one race
 - 7. Other (please specify): _____

- 88. Declined to answer/Refused
- 99. Unknown

Previous variable was ethnicity

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

2. What is your ethnicity? **ethnicity**

- 1. Hispanic or Latino
- 2. Not Hispanic or Latino

- 88. Declined to answer/Refused
- 99. Unknown

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

3. What is your dominant hand? **handdom**

- 1. Left
- 2. Right
- 3. Ambidextrous
- 99. Don't know

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

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

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.

Variable added in 2015, in addition to living before hospital discharge variable.

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

- 4. Parent or step-parent **livhisdis__4**
- 5. Other relative (siblings, grandparents) **livhisdis__5**
- 6. Others, not part of family **livhisdis__6**
- 7. Guardian **livhisdis__7**

- 88. Declined to answer/Refused
- 99. Unknown

3. How many years of education have you completed? **educdis**

Interviewer instructions: Ask the question as open-ended, and then mark the appropriate response below.

- 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
- 66. Other

- 88. Declined to answer/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) **disincdis** 88. Declined to answer/Refused

- 1. I am not receiving disability income 99. Unknown
- 2. Social Security Disability
- 3. Private long term insurance disability income
- 4. Supplemental security income (SSI)
- 5. Worker's compensation
- 6. Other **disincdiso**_____

Is there anything else you would like to tell us? _____

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

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: _____

Who is filling out this questionnaire? (Select all that apply)

1. Mother or stepmother proxydis__1 proxydis__77, not applicable (not proxy)
2. Father or stepfather proxydis__2
3. Guardian proxydis__3
4. Other proxydis__4

1. What is the method of administration of this form? admin

1. In person
2. Mail
3. Telephone interview
4. Online
5. Medical record review

2. What is the language of administration of this form? language

1. English
2. Spanish
3. Other

3. Checklist of forms: mark when each is complete status

1. Patient Status Form status__1 0 = not checked
2. Medical Record Abstraction Form status__2 1 = checked
3. Form I status__4

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. 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) next to that item. Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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 children 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. Some questions ask about what things were like before his/her burn injury, other questions are about your child's 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 your child best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Child Health Conditions*Interviewer instructions: Each question below is answered “yes” or “no”.**If answered “yes”, then ask “To what extent does this problem affect your child’s daily activities?”**Responses for this question are:*

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
-----------------	--------------------------------	---------------------------	------------------------------	----------------------------------	---------------------------	--------------------------------

Children’s development can be affected by the health problems that they experience. I will be asking you some questions about different health problems. I need to know whether or not your child has any of these problems. If your child has a health problem, I will be asking you to what extent the health problem affects your child’s daily activities.

Does your child have problems...	Problem?	1	2	3	4	5	6	7	
1. Seeing? chcprox1, chcprox1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
13. with Repeated infections? chcprox13, chcprox13a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
14. with Breathing (eg asthma)? chcself14, chcself14a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
17. with the Heart (such as a birth defect)? chcprox17, chcprox17a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
18. with Pain? chcprox18, chcprox18a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						

19. Does your child have any other health problems? **chcprox19** Yes No 0

If yes, specify problem: **chcprox19ot** (text field)

88. Declined to answer/Refused
99. Unknown

Pre-Injury History

The next section of questions is about your child's life and his/her 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 child's burn injury later in the interview.

Pre-Injury Demographics

1. Before your child's burn injury, where was he/she living? (Choose only one) **resdencprx**
- | | | |
|-----------------------------|--------------------------|--|
| 1. <input type="checkbox"/> | Private residence | <p>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. <input type="checkbox"/> | Nursing home | |
| 4. <input type="checkbox"/> | Correctional institution | |
| 5. <input type="checkbox"/> | Hotel/motel | |
| 6. <input type="checkbox"/> | Homeless | |
| 7. <input type="checkbox"/> | Hospital | |
2. What was your child's zip code at the time of his/her burn injury? ___ ___ ___ ___ ___ **zip_pre**
(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

Added to data collection forms in 2015.

3. Who was your child living with before his/her burn injury? (Choose all that apply)
- | | | | |
|-----------------------------|---|----------------------|---|
| 4. <input type="checkbox"/> | Parent or step-parent | livingaprx__4 | 0 = checked |
| 5. <input type="checkbox"/> | Other relative (siblings, grandparents) | livingaprx__5 | 1 = not checked |
| 6. <input type="checkbox"/> | Others, not part of family | livingaprx__6 | 88. <input type="checkbox"/> Declined to answer/Refused livingaprx__88 |
| 7. <input type="checkbox"/> | Guardian | livingaprx__7 | 99. <input type="checkbox"/> Unknown livingaprx__99 |

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn injury?". Also changed variable so that multiple answers were acceptable. Proxy variables added to differentiate between proxy and self-report.

4. Was your child enrolled in school at the time of his/her burn injury? (If yes) Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group? **aschoolprx**
- | | | |
|-----------------------------|--|---|
| 1. <input type="checkbox"/> | In school/age or above age appropriate | |
| 2. <input type="checkbox"/> | Not in school | 88. <input type="checkbox"/> Declined to answer/Refused |
| 3. <input type="checkbox"/> | In school/below age appropriate | 99. <input type="checkbox"/> Unknown |

Interviewer instructions: Skip to #6, below, if the child was going to school before the burn injury.

5. If your child was not enrolled in school at the time of his/her burn injury, why not? **whynotprx**
- | | | |
|-----------------------------|------------------------|---|
| 0. <input type="checkbox"/> | Not school age | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> | Other medical problems | 99. <input type="checkbox"/> Unknown |
| 4. <input type="checkbox"/> | Emotional/social | |
| 5. <input type="checkbox"/> | Legal/jail | |
| 6. <input type="checkbox"/> | Substance abuse | |
| 7. <input type="checkbox"/> | Personal choice | |
| 8. <input type="checkbox"/> | Other | |

6. Before his/her burn injury, did your child have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? **physprobpreprx**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

7. Before his/her burn injury, did your child have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimppreprx**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

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)? **psychlistprx**

1. Depression
2. Bipolar disorder
3. Anxiety
4. Post-Traumatic Stress Disorder (PTSD)
5. Schizophrenia/psychotic disorder
6. Other, please explain: _____

88. Declined to answer/Refused
99. Unknown

0=No

Additional variables *psychlist2prx* and *psychlist3prx* are in the database with the same coding in case a participant endorses more than one issue.

Pain Medication

1. In the month before your child's burn injury did he/she take prescription medication for pain on a regular basis? **pmedprx_pre**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

2. In the past 12 months, did your child take medication for being, worried, tense, or anxious? **wmedprx_pre**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

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

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

These questions added with new forms in December 2015.

4. Did your child receive psychological therapy or counseling in the last 12 months? **psychtherprx**

1. Yes
2. No

88. Declined to answer/Refused
99. Unknown

Demographics

Interviewer Instructions: Use medical record for #1-3. Skip these questions unless self-report is best source, and record answer onto the Form I Medical Record Abstraction Form along with source of data.

1. What is your child's racial group? **raceprx**

1. Black or African-American
2. Asian
3. Caucasian (white)
4. American Indian/Alaskan Native
5. Native Hawaiian or Other Pacific Islander
6. More than one race
7. Other (please specify): _____

88. Declined to answer/Refused
99. Unknown

Previous variable was ethnicity.

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

2. What is your child's ethnicity? **ethnicityprx**

1. Hispanic or Latino
2. Not Hispanic or Latino

88. Declined to answer/Refused
99. Unknown

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

3. What is your child's dominant hand? **handdomprx**

1. Left
2. Right
3. Ambidextrous
99. Don't know

88. Declined to answer/Refused
99. Unknown

1. After your child's hospital discharge, where will he/she be living? (Choose only one)

dislivsitprx

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

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

4. Parent or step-parent **livingaprx__4** 0 = not checked
5. Other relative (siblings, grandparents) **livingaprx__5** 1 = checked
6. Others, not part of family **livingaprx__6**
7. Guardian **livingaprx__7**

88. Declined to answer/Refused **livingaprx__88**
99. Unknown **livingaprx__99**

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn

injury?". Also changed variable so that multiple answers were acceptable. Proxy variables added to differentiate between proxy and self-report.

3. How many years of education has your child completed? educdisprx

Interviewer instructions: Ask the question as open-ended, and then mark the appropriate response below.

- | | |
|---|---|
| 0. <input type="checkbox"/> Preschool completed | 88. <input type="checkbox"/> Declined to answer/Refused |
| 1. <input type="checkbox"/> 1 year or less | 99. <input type="checkbox"/> Unknown |
| 2. <input type="checkbox"/> 2 years | |
| 3. <input type="checkbox"/> 3 years | |
| 77. <input type="checkbox"/> Not applicable (child is too young for school) | |

4. Approximately what was your household's total income in the last full year before your child's burn injury (total income of all members of the household)?

If clarification is needed about the reason this question is asked, , say, "Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds." hinccatpreprx

If clarification about currency is needed, say, "these categories are in U.S. dollar amounts."

- | |
|--|
| 1. <input type="checkbox"/> Less than \$25,000 |
| 2. <input type="checkbox"/> \$25,000-\$49,999 |
| 3. <input type="checkbox"/> \$50,000-\$99,999 |
| 4. <input type="checkbox"/> \$100,000-\$149,999 |
| 5. <input type="checkbox"/> \$150,000-\$199,999 |
| 6. <input type="checkbox"/> \$200,000 or more |
| 7. <input type="checkbox"/> Living outside the United States |
| 77. <input type="checkbox"/> Not applicable (e.g., living in an institution) |

5. How many people are in your household? numhspreprx

(Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

Interviewer instructions: If the child is under the age of 3 years, ask the question below and then you are finished with the interview. If the child is between 3 and 7 years old, continue with the General Life Satisfaction section on the last page.

Is there anything else you would like to tell us? _____

We're done. 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.

Indicate time survey ended: _____

Interviewer instructions: If the child is between 3 and 7 years old, continue with the General Life Satisfaction section, below.

NIH Toolbox General Life Satisfaction

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

88 / 99

88 / 99

Is there anything else you would like to tell us? _____

We're done. 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.

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: _____

Follow-up Information: *Interviewer instructions: Fill this page out before beginning the interview with the participant.*

1. Follow-up period **follow_up**

- 1. 6-month follow-up
- 2. 12-month follow-up
- 3. 24-month follow-up
- 4. 5 year follow-up
- 5. 10 year follow-up

Previous variable was called "followup". For this new variable, additional time-points have been added. In the previous iteration, "followup", 4-Other.

2. What is the method of administration of this form? **admin_fup**

- 1. In person
- 2. Mail
- 3. Telephone interview
- 4. Online
- 5. Medical record review

Previous variable was called "admin_2". For this new variable, additional options have been added— Online and Medical record review.

3. What is the language of administration of this form? **language_fup**

- 1. English
- 2. Spanish
- 3. Other

Previous variable was called "admin_2".

4. What is the status of this follow-up assessment? (Choose only one) **lostfolo**

- 1. Some or all assessment done
- 2. Death due to burn related complications
- 3. Death due to non-burn related complications
- 4. Unable to locate
- 5. Refused this assessment
- 6. Unable to test/med comp/incapable of responding
- 7. Failed to respond
- 8. Did not consent to future assessment/withdrew
- 11. Incarcerated
- 13. Still in hospital (not discharged yet)
- 14. Unable to travel for assessment
- 15. Death (unknown causes)

Interviewer Instructions: Update date and cause of death on Patient Status Form

Option 14 added with new forms in 2015
Option 15 added with new forms in 2018

Interviewer Instructions: *Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. Have the updated Patient Status form with you to help with the interview.*

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) next to that item.

Replace the introduction script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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 of children with burn injuries. Like our previous interviews, I'll be asking questions about your burn injury and other questions about you and people around you. Your answers will help us understand the experiences of kids with burn injury. 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."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Body Image

The following questions ask about your appearance:

	Definitely true=1	Mostly true=2	Not sure=3	Mostly false=4	Definitely false=5	
1. I feel that the burn is unattractive to others. bodyim_1	<input type="checkbox"/>	88 / 99				
2. I think people would not want to touch me. bodyim_2	<input type="checkbox"/>	88 / 99				
3. I feel unsure of myself among strangers. bodyim_3	<input type="checkbox"/>	88 / 99				
4. Changes in my appearance have interfered with my relationships. bodyim_4	<input type="checkbox"/>	88 / 99				

Body Image Self-Report Total Score: **bodyim_tot_self**

CPSS – Part I:

I'm going to read a list of problems that kids sometimes have after experiencing an upsetting event. I will read each one carefully to you and then tell me 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=0	Once a week or less/ once in a while=1	2 to 4 times a week/ half the time=2	5 or more times a week/ almost always=3	
1. Having upsetting thoughts or images about your burn injury that came into your head when you didn't want them to cpss_1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Having bad dreams or nightmares cpss_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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) cpss_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc) cpss_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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) cpss_5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. Trying not to think about, talk about, or have feelings about your burn injury cpss_6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. Trying to avoid activities, people, or places that remind you of your burn injury cpss_7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. Not being able to remember an important part of your burn injury cpss_8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

9. Having much less interest or doing things you used to do cpss_9	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. Not feeling close to people around you cpss_10	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) cpss_11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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) cpss_12	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
	Not at all or only at one time=0	Once a week or less/ once in a while=1	2 to 4 times a week/ half the time=2	5 or more times a week/ almost always=3	
13. Having trouble falling or staying asleep cpss_13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
14. Feeling irritable or having fits of anger cpss_14	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class) cpss_15	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
16. Being overly careful (for example, checking to see who is around you and what is around you) cpss_16	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
17. Being jumpy or easily startled (for example, when someone walks up behind you) cpss_17	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

CPSS Total Score Variable: cpss_tot_score

PROMIS Anger

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt mad pr206r1	<input type="checkbox"/>	88 / 99				
2. I felt upset pr714r1	<input type="checkbox"/>	88 / 99				
3. I felt fed up pr5045r1	<input type="checkbox"/>	88 / 99				
4. I was so angry I felt like throwing something pr2319ar1	<input type="checkbox"/>	88 / 99				
5. I was so angry I felt like yelling at somebody pr2581r1	<input type="checkbox"/>	88 / 99				

PROMIS Anger Total Score Pediatric: angtscore_ped

PROMIS 25

Physical function mobility

In the past 7 days...	0=with no trouble	1=with a little trouble	2= With some trouble	3= With a lot of trouble	4=Not able to do

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric 8-12 Interview Form II
NewMSID_____

1. I could do sports and exercise that other kids my age could do pr235r1	<input type="checkbox"/>	88 / 99				
2. I could get up from the floor pr4124r1	<input type="checkbox"/>	88 / 99				
3. I could walk up stairs without holding on to anything pr2707r2	<input type="checkbox"/>	88 / 99				
4. I have been physically able to do the activities I enjoy most pr5023r1	<input type="checkbox"/>	88 / 99				

PROMIS-25 Physical Function T-Score: **pftscore_ped**

Anxiety

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt like something awful might happen pr2220r2	<input type="checkbox"/>	88 / 99				
2. I felt nervous pr713r1	<input type="checkbox"/>	88 / 99				
3. I felt worried pr5044r1	<input type="checkbox"/>	88 / 99				
4. I worried when I was at home pr3459br1	<input type="checkbox"/>	88 / 99				

PROMIS-25 Anxiety T-Score: **anxtscore_ped**

Depressive Symptoms

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt everything in my life went wrong pr5041r1	<input type="checkbox"/>	88 / 99				
2. I felt lonely pr711r1	<input type="checkbox"/>	88 / 99				
3. I felt sad pr228r1	<input type="checkbox"/>	88 / 99				
4. It was hard for me to have fun pr3952ar2	<input type="checkbox"/>	88 / 99				

PROMIS-25 Depression T-Score: **deptscore_ped**

Fatigue

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. Being tired made it hard for me to keep up with my schoolwork pr4239ar2	<input type="checkbox"/>	88 / 99				
2. I got tired easily pr2876r1	<input type="checkbox"/>	88 / 99				
3. I was too tired to do sports or exercise pr4241r2	<input type="checkbox"/>	88 / 99				

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

4. I was too tired to enjoy the things I like to do pr4196r1	<input type="checkbox"/>				
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88 / 99

PROMIS-25 Fatigue T-Score: **fattscore_ped**

Peer relationships

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always
1. I felt accepted by other kids my age pr5018r1	<input type="checkbox"/>				
2. I was able to count on my friends pr5058r1	<input type="checkbox"/>				
3. My friends and I helped each other out pr5055r1	<input type="checkbox"/>				
4. Other kids wanted to be my friend pr233r2	<input type="checkbox"/>				

88 / 99

88 / 99

88 / 99

88 / 99

PROMIS-25 Peer Relationships T-Score: **peertscore_ped**

Pain Interference

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always
1. I had trouble sleeping when I had pain pr3793r1	<input type="checkbox"/>				
2. It was hard for me to pay attention when I had pain pr9004	<input type="checkbox"/>				
3. It was hard for me to run when I had pain pr2045r1	<input type="checkbox"/>				
4. It was hard for me to walk one block when I had pain pr2049r1	<input type="checkbox"/>				

88 / 99

88 / 99

88 / 99

88 / 99

PROMIS-25 Pain Interference T-Score: **painintscore_ped**

Pain Intensity

In the past 7 days...

How bad was your pain on average? **pr9033r1**

88. Declined to answer/Refused

99. Unknown

<input type="checkbox"/>										
0-No pain	1	2	3	4	5	6	7	8	9	10-Worst pain you can think of

NIH TB General Life Satisfaction Short Form/Fixed Form Ages 8-12

Indicate how much you agree or disagree...	Strongly Disagree=1	Disagree=2	Neither Agree nor Disagree=3	Agree=4	Strongly Agree=5
1. My life is going well pa066	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88 / 99

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric 8-12 Interview Form II
NewMSID _____

2. My life is just right pa067	<input type="checkbox"/>	88 / 99				
3. I have a good life pa070	<input type="checkbox"/>	88 / 99				
4. I have what I want in life pa071	<input type="checkbox"/>	88 / 99				

NIH General Life Satisfaction Self-report T-Score: **tbglstscore8_12_ped**

BMS-Itch (based on PROMIS pain interference and modified for BMS)

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I had trouble sleeping when I was itching bmsitch_1	<input type="checkbox"/>	88 / 99				
2. I felt angry when I was itching bmsitch_2	<input type="checkbox"/>	88 / 99				
3. I had trouble doing schoolwork when I was itching bmsitch_3	<input type="checkbox"/>	88 / 99				
4. It was hard for me to pay attention when I was itching bmsitch_4	<input type="checkbox"/>	88 / 99				
5. It was hard for me to have fun when I was itching bmsitch_5	<input type="checkbox"/>	88 / 99				

PTGI-C:

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

Tell me for each of the next statements the degree to which this change happened in your life as a result of your burn injury.

Question	0=No change	1=A little	2= Some	3=A lot	99= Don't know	
1. I learned how nice and helpful some people can be. ptgic_1	<input type="checkbox"/>	88/Refused				
2. I can now handle big problems better than I used to. ptgic_2	<input type="checkbox"/>	88/Refused				
3. I know what is important to me better than I used to. ptgic_3	<input type="checkbox"/>	88/Refused				
4. I understand how God works better than I used to. ptgic_4	<input type="checkbox"/>	88/Refused				
5. I feel closer to other people (friends or family) than I used to. ptgic_5	<input type="checkbox"/>	88/Refused				
6. I appreciate (enjoy) each day more than I used to. ptgic_6	<input type="checkbox"/>	88/Refused				

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric 8-12 Interview Form II
NewMSID_____

7. I now have a chance to do some things I couldn't do before. ptgic_7	<input type="checkbox"/>	88/Refused				
8. My faith (belief) in God is stronger than it was before. ptgic_8	<input type="checkbox"/>	88/Refused				
9. I have learned that I can deal with more things than I thought I could before. ptgic_9	<input type="checkbox"/>	88/Refused				
10. I have new ideas about how I want things to be when I grow up. ptgic_10	<input type="checkbox"/>	88/Refused				

Post-Traumatic Growth Inventory Child Total Score: **ptgictot**

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: _____

Who is filling out this questionnaire? (Select all that apply)

- 1. Mother or stepmother proxy__1 proxy__77, not applicable (not proxy)
- 2. Father or stepfather proxy__2
- 3. Guardian proxy__3
- 4. Other proxy__4

1. What is the method of administration of this form? admin

- 1. In person
- 2. Mail
- 3. Telephone interview
- 4. Online
- 5. Medical record review

2. What is the language of administration of this form? language

- 1. English
- 2. Spanish
- 3. Other

3. Checklist of forms: mark when each is complete status

- 1. Patient Status Form status__1
 - 2. Medical Record Abstraction Form status__2
 - 3. Form I status__4
- 0 = not checked
1 = checked

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. 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) next to that item. Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Child Health Conditions

Interviewer instructions: Each question below is answered “yes” or “no”.

If answered “yes”, then ask “To what extent does this problem affect your child’s daily activities?”

Responses for this question are:

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>
------------------------	------------------------------------	-------------------------------	----------------------------------	--------------------------------------	-------------------------------	------------------------------------

Children’s development can be affected by the health problems that they experience. I will be asking you some questions about different health problems. I need to know whether or not your child has any of these problems. If your child has a health problem, I will be asking you to what extent the health problem affects your child’s daily activities.

Do you have problems...	Problem?	1	2	3	4	5	6	7	
1. Seeing? chcprox1, chcprox1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
13. with Repeated infections? chcprox13, chcself13a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
14. with Breathing (eg asthma)? chcprox14, chcprox14a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
17. with the Heart (such as a birth defect)? chcprox17, chcprox17a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
18. with Pain? chcprox18, chcprox18a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						

19. Does your child have any other health problems? 1Yes 0No

chcprox19

If yes, specify problem: **chcprox19ot (text field)** _____

88. Declined to answer/Refused

99. Unknown

Pre-Injury History

The next section of questions is about your child’s life and his/her 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 child’s burn injury later in the interview.

NIH Toolbox General Life Satisfaction

Indicate how much you agree or disagree:

In the four weeks before my child’s burn...	1= Strongly disagree	2= Disagree	3= Neither agree nor disagree	4= Agree	5= Strongly agree	
1. My child's life was going well. <i>papxy066pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My child's life was just right. <i>papxy067pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. My child had a good life. <i>papxy070pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. My child had what he/she wanted in life. <i>papxy071pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

Pre-Injury Demographics

1. Before your child’s burn injury, where was he/she living? (Choose only one) *resdencprx*
- 1. Private residence
 - 2. Nursing home
 - 4. Correctional institution
 - 5. Hotel/motel
 - 6. Homeless
 - 7. Hospital
- 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 child’s zip code at the time of his/her burn injury? _____ *zipprx_pre*
(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

3. Who was your child living with before his/her burn injury? (Choose all that apply)
- 4. Parent or step-parent *livingaprx__4*
 - 5. Other relative (siblings, grandparents) *livingaprx__5*
 - 6. Others, not part of family *livingaprx__6* 88. Declined to answer/Refused *livingaprx__88*
 - 7. Guardian *livingaprx__7* 99. Unknown *livingaprx__99*
- 0=not checked
1=checked

The previous variable “living” was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to “other relative” option to include “siblings, grandparents”, “other”, to include “not part of family”. At this time, wording was changed from “living with at time of burn” to “who were you living with before your burn

injury?". Also changed variable so that multiple answers were acceptable. Proxy variables added to differentiate between proxy and selfreport.

4. Was your child enrolled in school at the time of his/her burn injury? (If yes) Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group? **aschoolprx**

- 1. In school/age or above age appropriate
- 2. Not in school
- 3. In school/below age appropriate
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer instructions: Skip to #6, below, if the child was going to school before the burn injury.

5. If your child was not enrolled in school at the time of his/her burn injury, why not? **whynotprx**

- 2. Other medical problems
- 4. Emotional/social
- 5. Legal/jail
- 6. Substance abuse
- 7. Personal choice
- 8. Other
- 88. Declined to answer/Refused
- 99. Unknown

6. Before the burn, did your child have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? **physprobpreprx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

7. Before the burn, did your child have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimppreprx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

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)? **psychlistprx**

- 1. Depression
- 2. Bipolar disorder
- 3. Anxiety
- 4. Post-Traumatic Stress Disorder (PTSD)
- 5. Schizophrenia/psychotic disorder
- 6. Other, please explain: _____ **psychlistotprx**
- 88. Declined to answer/Refused
- 99. Unknown

Two other variables are in the database, **psychlist2prx** and **psychlist3prx**, in case more than one issue is endorsed (same coding as above).

Pain Medication

1. In the month before your child's burn injury did he/she take prescription medication for pain on a regular basis? **pmedprx_pre**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

2. In the past 12 months, did your child take medication for being, worried, tense, or anxious? **wmedprx_pre**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

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

smedprx_pre

- 1. Yes
- 2. No

- 88. Declined to answer/Refused
- 99. Unknown

4. Did your child receive psychological therapy or counseling in the last 12 months? psychtherprx

- 1. Yes
- 2. No

- 88. Declined to answer/Refused
- 99. Unknown

Demographics

Interviewer Instructions: Use medical record for #1-3. Skip these questions unless self-report is best source, and record answer onto the Form I Medical Record Abstraction Form along with source of data.

1. What is your child's racial group? raceprx

- 1. Black or African-American
- 2. Asian
- 3. Caucasian (white)
- 4. American Indian/Alaskan Native
- 5. Native Hawaiian or Other Pacific Islander
- 6. More than one race
- 7. Other (please specify):_____

- 88. Declined to answer/Refused
- 99. Unknown

Previous variable was ethnicity.

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

2. What is your child's ethnicity? ethnicityprx

- 1. Hispanic or Latino
- 2. Not Hispanic or Latino

- 88. Declined to answer/Refused
- 99. Unknown

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.

3. What is your child's dominant hand? handdomprx

- 1. Left
- 2. Right
- 3. Ambidextrous
- 99. Don't know

- 88. Declined to answer/Refused
- 99. Unknown

1. After your child's hospital discharge, where will he/she be living? (Choose only one)

dislivsitprx

- 1. Private residence
- 2. Nursing home
- 4. Correctional institution

- 88. Declined to answer/Refused
- 99. Unknown

- 5. Hotel/motel
- 6. Homeless
- 7. Hospital

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

- 4. Parent or step-parent livingaprx__4
- 5. Other relative (siblings, grandparents) livingaprx__5
- 6. Others, not part of family livingaprx__6
- 7. Guardian livingaprx__7
- 88. Declined to answer/Refused livingaprx__88
- 99. Unknown livingaprx__99

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn injury?". Also changed variable so that multiple answers were acceptable. Proxy variables added to differentiate between proxy and self-report.

3. How many years of education has your child completed? educdisprx

Interviewer instructions: Ask the question as open-ended, and then mark the appropriate response below.

- 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
- 66. Other
- 88. Declined to answer/Refused
- 99. Unknown

4. Approximately what was your household's total income in the last full year before your burn injury (total income of all members of the household)?

If clarification is needed about the reason this question is asked, , say, "Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds."

If clarification about currency is needed, say, "these categories are in U.S. dollar amounts."

hinccatpreprx

- 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)

5. How many people are in your household? numhspreprx

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

- 1. My child is not receiving disability income
- 2. Social Security Disability
- 3. Private long term insurance disability income
- 4. Supplemental security income (SSI)
- 5. Worker's compensation
- 6. Other disincondisopr
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer instructions: If the child is younger than 14, ask the question below and then you are finished with the interview. If the child is 14 or older, continue with the Pre-Burn CIQ, below.

Is there anything else you would like to tell us? _____

We're done. 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.

Indicate time survey ended: _____

Interviewer instructions: If the child is 14 or older, continue with the Pre-Burn CIQ, below.

CIQ Pre:

Finally, I have a few more questions that ask about the time before your child's burn injury. This is the last section of the interview.

These questions about some activities your child might have participated in before his/her burn injury.

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. Declined to answer/Refused
- 99. Unknown

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

2: Shopping **ci3prx_pre**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times

- 88. Declined to answer/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. Declined to answer/Refused
- 99. Unknown

4: Visiting friends or relatives **ci5prx_pre**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times

- 88. Declined to answer/Refused
- 99. Unknown

During the 4 weeks before your child's burn:

5: When your child participated in leisure activities did he/she usually do this alone or with others?

ci6prx_pre

- 1. Mostly alone
- 3. Mostly with family members
- 4. Mostly with friends *who do not have burn injuries*
- 5. With a combination of family and friends
- 77. Not applicable (no leisure activities)

- 88. Declined to answer/Refused
- 99. Unknown

6: Did your child have a best friend with whom he/she confided? **ci7prx_pre**

- 1. Yes
- 2. No

- 88. Declined to answer/Refused
- 99. Unknown

CIQ Social Integration Proxy Total Score: ciqsicprx_pre

Is there anything else you would like to tell us? _____

We're done. 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.

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: _____

Follow-up Information: *Interviewer instructions: Fill this page out before beginning the interview with the participant.*

1. Follow-up period **follow_up**

- 1. 6-month follow-up
- 2. 12-month follow-up
- 3. 24-month follow-up
- 4. 5 year follow-up
- 5. 10 year follow-up
- 6. 15 year follow-up

Previous variable was called "followup". For this new variable, additional time-points have been added. In the previous iteration, "followup", 4-Other.

2. What is the method of administration of this form? **admin_fup**

- 1. In person
- 2. Mail
- 3. Telephone interview
- 4. Online
- 5. Medical record review

Previous variable was called "admin_2". For this new variable, additional options have been added — Online and Medical record review.

3. What is the language of administration of this form? **language_fup**

- 1. English
- 2. Spanish
- 3. Other

Previous variable was called "admin_2".

4. What is the status of this follow-up assessment? (Choose only one) **lostfolo**

- 1. Some or all assessment done
- 2. Death due to burn related complications
- 3. Death due to non-burn related complications
- 4. Unable to locate
- 5. Refused this assessment
- 6. Unable to test/med comp/incapable of responding
- 7. Failed to respond
- 8. Did not consent to future assessment/withdrew
- 11. Incarcerated
- 13. Still in hospital (not discharged yet)
- 14. Unable to travel for assessment
- 15. Death (unknown causes)

Interviewer Instructions: Update date and cause of death on Patient Status Form

Option 14 added with new forms in 2015
Option 15 added with new forms in 2018

Interviewer Instructions: *Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. Have the updated Patient Status form with you to help with the interview.*

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) next to that item.

Replace the introduction script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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 of young people with burn injuries. Like our previous interviews, I'll be asking questions about your burn injury and other questions about you and people around you. Your answers will help us understand the experiences of all people with burn injury. 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."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Burn Injury Follow-up

First I have some questions related to your burn injury...

1. Since your last interview, have you spoken with other burn survivors to get support for problems related to your burn injury? **peersup** 88. Declined to answer/Refused

- 1. Yes
- 2. No

99. Unknown

Added in 2015

2. Since the last interview, have you received any of the following services at home or outpatient? (*Choose all that apply*)

If clarification is needed: 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.

- 1. No services (*Interviewer Instructions: skip to #6, surgery item, on page 4*) **services__1**
- 2. Occupational therapy **services__2**
- 3. Physical therapy **services__3** 88. Declined to answer/Refused
- 4. Speech language pathology **services__4** 99. Unknown
- 5. Social work **services__5**
- 6. Psychological services or child life services **services__6** 0 = not checked
- 7. Vocational services **services__7** 1 = checked

Added in 2015

Interviewer Instructions: if participant indicates that services were received but that those services were not occupational and/or physical therapy, skip to #6, surgery item, on page 4.

Interviewer Instructions: Continue with these questions if the participant received OT and/or PT...

3. How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? **numserv**

- 1. One
- 2. 2-4
- 3. 5-10
- 4. More than 10

88. Declined to answer/Refused
99. Unknown

77. No PT/OT (*skip to #6, surgery item, on page 4*)

Since your last interview, where did you receive your outpatient occupational or physical burn therapy?

4. This clinical burn center? **ther_brn_cntr** 88. Declined to answer/Refused

- 1. Yes
- 2. No

99. Unknown

77. Not applicable (no OT/PT received)

New coding for 77/88/99 added in 2015

5. Other facility? **ther_otr**

- 1. Yes
- 2. No

88. Declined to answer/Refused
99. Unknown

77. Not applicable (no OT/PT received)

New coding for 77/88/99 added in 2015

6. Since your last interview [*provide date*], have you had any burn related surgeries(such as surgeries for open wounds or scar management)? **surgery_fu**

1. Yes
 2. No (*Interviewer Instructions: skip to Child Health Conditions on page x*)
 99. Don't know (*Interviewer Instructions: skip to Child Health Conditions on page x*)
 88. Declined to answer/Refused

New coding for 88/99 added in 2015

Interviewer Instructions: Continue with this question if the participant had burn related surgeries

7. Have you had any burn-related surgeries outside of [*name the BMS center*]? **surgout**

1. Yes
 2. No
 99. Don't know
 88. Declined to answer/Refused

Added in 2015

Child Health Conditions

Interviewer instructions: Each question below is answered "yes" or "no".

If answered "yes", then ask "To what extent does this problem affect your daily activities?"

Responses for this question are:

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>
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Now, I'd like to ask some questions about your current health and medical condition. For any conditions that you have, I'll ask you to what extent the condition affects your daily activities.

Do you have problems...	Problem?	1	2	3	4	5	6	7	
1. Seeing? chcself1, chcself1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
2. Hearing? chcself2, chcself2a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
3. Learning and understanding? chcself3, chcself3a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcself4, chcself4a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
5. Controlling emotions or behavior? chcself5, chcself5a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
6. with Seizures or epilepsy? chcself6, chcself6a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcself7, chcself7a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
8. with Teeth and gums? chcself8, chcself8a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
10. with Type 1 or Type 2 diabetes? chcself10, chcself10a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						
11. with Growth? chcself11, chcself11a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99						

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	
12. Sleeping? chcself12, chcself12a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
13. with Repeated infections? chcself13, chcself13a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
14. with Breathing (eg asthma)? chcself14, chcself14a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
16. with other Skin problems (eg eczema)? chcself16, chcself16a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
17. with the Heart (such as a birth defect)? chcself17, chcself17a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
18. with Pain? chcself18, chcself18a				<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

19. Do you have any other health problems? **chcself19** Yes No
 If yes, specify problem: _____ **chcself19ot (text field)** 88. Declined to answer/Refused
 99. Unknown

Pain Medication

1. In the **past month** did you take prescription medication for pain on a regular basis? **pmed**
 1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

2. In the **past month** did you take prescription medication for itch on a regular basis? **imed**
 1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

3. In the **past 12 months**, did you take medication for being, worried, tense, or anxious? **wmed**
 1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

4. In the **past 12 months**, did you take medication for being sad, empty, or depressed? **smed**
 1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

5. Since your last research study questionnaire, have you received psychological therapy or counseling due to your burn injury? **psychther**
 1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

Body Image

The following questions ask about your appearance:

	Definitely true=1	Mostly true=2	Not sure=3	Mostly false=4	Definitely false=5	
1. I feel that the burn is unattractive to others. <i>bodyim_1</i>	<input type="checkbox"/>	88 / 99				
2. I think people would not want to touch me. <i>bodyim_2</i>	<input type="checkbox"/>	88 / 99				
3. I feel unsure of myself among strangers. <i>bodyim_3</i>	<input type="checkbox"/>	88 / 99				
4. Changes in my appearance have interfered with my relationships. <i>bodyim_4</i>	<input type="checkbox"/>	88 / 99				

CPSS – Part I:

I'm going to read a list of problems that kids sometimes have after experiencing an upsetting event. I will read each one carefully to you and then tell me 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=0	Once a week or less/ once in a while=1	2 to 4 times a week/ half the time=2	5 or more times a week/ almost always=3	
1. Having upsetting thoughts or images about your burn injury that came into your head when you didn't want them to <i>cpss_1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Having bad dreams or nightmares <i>cpss_2</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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) <i>cpss_3</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc) <i>cpss_4</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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) <i>cpss_5</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. Trying not to think about, talk about, or have feelings about your burn injury <i>cpss_6</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. Trying to avoid activities, people, or places that remind you of your burn injury <i>cpss_7</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. Not being able to remember an important part of your burn injury <i>cpss_8</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. Having much less interest or doing things you used to do <i>cpss_9</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. Not feeling close to people around you <i>cpss_10</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) cpss_11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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) cpss_12	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
I'm going to read a list of problems that kids sometimes have after experiencing an upsetting event. I will read each one carefully to you and then tell me 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=0	Once a week or less/ once in a while=1	2 to 4 times a week/ half the time=2	5 or more times a week/ almost always=3	
13. Having trouble falling or staying asleep cpss_13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
14. Feeling irritable or having fits of anger cpss_14	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class) cpss_15	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
16. Being overly careful (for example, checking to see who is around you and what is around you) cpss_16	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
17. Being jumpy or easily startled (for example, when someone walks up behind you) cpss_17	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

CPSS Total Score Variable: cpss_tot_score

PROMIS Anger

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt mad pr206r1	<input type="checkbox"/>	88 / 99				
2. I felt upset pr714r1	<input type="checkbox"/>	88 / 99				
3. I felt fed up pr5045r1	<input type="checkbox"/>	88 / 99				
4. I was so angry I felt like throwing something pr2319ar1	<input type="checkbox"/>	88 / 99 88 / 99				
5. I was so angry I felt like yelling at somebody pr258r1	<input type="checkbox"/>					

PROMIS Anger Total Score Pediatric: angtscore_ped

PROMIS 25

Physical function mobility

In the past 7 days...	0=with no trouble	1=with a little trouble	2= With some trouble	3= With a lot of trouble	4=Not able to do	
1. I could do sports and exercise that other kids my age could do pr235r1	<input type="checkbox"/>	88 / 99				
2. I could get up from the floor pr4124r1	<input type="checkbox"/>	88 / 99				

3. I could walk up stairs without holding on to anything pr2707r2	<input type="checkbox"/>	88 / 99				
4. I have been physically able to do the activities I enjoy most pr5023r1	<input type="checkbox"/>	88 / 99				

PROMIS Physical Function T-Score Variable: **pftscore_ped**

Anxiety

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt like something awful might happen pr2220r2	<input type="checkbox"/>	88 / 99				
2. I felt nervous pr713r1	<input type="checkbox"/>	88 / 99				
3. I felt worried pr5044r1	<input type="checkbox"/>	88 / 99				
4. I worried when I was at home pr3459br1	<input type="checkbox"/>	88 / 99				

PROMIS Anxiety T-Score Variable: **anxtscore_ped**

Depressive Symptoms

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt everything in my life went wrong pr5041r1	<input type="checkbox"/>	88 / 99				
2. I felt lonely pr711r1	<input type="checkbox"/>	88 / 99				
3. I felt sad pr228r1	<input type="checkbox"/>	88 / 99				
4. It was hard for me to have fun pr3952r1	<input type="checkbox"/>	88 / 99				

PROMIS Depressive Symptoms T-Score Variable: **deptscore_ped**

Fatigue

In the past 7 days...	0= Nev er	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. Being tired made it hard for me to keep up with my schoolwork pr4239ar2	<input type="checkbox"/>	88 / 99				
2. I got tired easily pr2876r1	<input type="checkbox"/>	88 / 99				
3. I was too tired to do sports or exercise pr4241r2	<input type="checkbox"/>	88 / 99				
4. I was too tired to enjoy the things I like to do pr4196r1	<input type="checkbox"/>	88 / 99				

PROMIS Fatigue T-Score Variable: **fatscore_ped**

Peer relationships

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt accepted by other kids my age pr5018r1	<input type="checkbox"/>	88 / 99				
2. I was able to count on my friends pr5058r1	<input type="checkbox"/>	88 / 99				
3. My friends and I helped each other out pr5055r1	<input type="checkbox"/>	88 / 99				
4. Other kids wanted to be my friend pr233r2	<input type="checkbox"/>	88 / 99				

PROMIS Peer Relationships T-Score Variable: **peertscore_ped**

Pain Interference

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I had trouble sleeping when I had pain pr3793r1	<input type="checkbox"/>	88 / 99				
2. It was hard for me to pay attention when I had pain pr9004	<input type="checkbox"/>	88 / 99				
3. It was hard for me to run when I had pain pr2045r1	<input type="checkbox"/>	88 / 99				
4. It was hard for me to walk one block when I had pain pr2049r1	<input type="checkbox"/>	88 / 99				

PROMIS Pain Interference T-Score Variable: **painintscore_ped**

Pain Intensity

In the past 7 days...

How bad was your pain on average? **pr9033r1**

88. Declined to answer/Refused

99. Unknown

<input type="checkbox"/>										
0-No pain	1	2	3	4	5	6	7	8	9	10-Worst pain you can think of

NIH TB General Life Satisfaction CAT Ages 13-17

Indicate how much you agree or disagree...	Strongly Disagree=1	Disagree=2	Neither Agree nor Disagree=3	Agree=4	Strongly Agree=5	
1. My life is going well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My life is just right	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I have a good life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I have what I want in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

GLS Total Score Variable: **tbgilstscore13_17_ped**

CIQ:

The next questions I have are about some activities you might have participated in recently.

Currently:

1. Did you take responsibility for personal grooming when asked? **ci2**
- 1. Often
 - 2. Sometimes
 - 3. Never
 - 88. Declined to answer/Refused
 - 99. Unknown

Approximately how many times a month do you usually participate in the following activities outside of your home?

- 2: Shopping **ci3**
- 1. Never
 - 2. 1-4 times
 - 3. 5 or more times
 - 88. Declined to answer/Refused
 - 99. Unknown

- 3: Leisure activities such as movies, sports, and restaurants. **ci4**
- 1. Never
 - 2. 1-4 times
 - 3. 5 or more times
 - 88. Declined to answer/Refused
 - 99. Unknown

- 4: Visiting friends or relatives **ci5**
- 1. Never
 - 2. 1-4 times
 - 3. 5 or more times
 - 88. Declined to answer/Refused
 - 99. Unknown

- 5: When you participate in leisure activities do you usually do this alone or with others? **ci6**
- 1. Mostly alone
 - 2. Mostly with friends who have burn injuries
 - 3. Mostly with family members
 - 4. Mostly with friends who do not have burn injuries
 - 5. With a combination of family and friends
 - 77. Not applicable (no leisure activities)
 - 88. Declined to answer/Refused
 - 99. Unknown

- 6: Do you have a best friend with whom you confide? **ci7**
- 1. Yes
 - 2. No
 - 88. Declined to answer/Refused
 - 99. Unknown

CIQ Social Integration Total Score: ciqsic

BMS-Itch (based on PROMIS pain interference and modified for BMS)

In the past 7 days...	0= Never	1= Almost Never	2= Some- times	3= Often	4=Almost always
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1. I had trouble sleeping when I was itching bmsitch_1	<input type="checkbox"/>	88 / 99				
2. I felt angry when I was itching bmsitch_2	<input type="checkbox"/>	88 / 99				
3. I had trouble doing schoolwork when I was itching bmsitch_3	<input type="checkbox"/>	88 / 99				
4. It was hard for me to pay attention when I was itching bmsitch_4	<input type="checkbox"/>	88 / 99				
5. It was hard for me to have fun when I was itching bmsitch_5	<input type="checkbox"/>	88 / 99				

PTGI-C:

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

Tell me for each of the next statements the degree to which this change happened in your life as a result of your burn injury.

Question	0=No change	1=A little	2=Some	3=A lot	99=Don't know	
1. I learned how nice and helpful some people can be. ptgic_1	<input type="checkbox"/>	88/Refused				
2. I can now handle big problems better than I used to. ptgic_2	<input type="checkbox"/>	88/Refused				
3. I know what is important to me better than I used to. ptgic_3	<input type="checkbox"/>	88/Refused				
4. I understand how God works better than I used to. ptgic_4	<input type="checkbox"/>	88/Refused				
5. I feel closer to other people (friends or family) than I used to. ptgic_5	<input type="checkbox"/>	88/Refused				
6. I appreciate (enjoy) each day more than I used to. ptgic_6	<input type="checkbox"/>	88/Refused				
7. I now have a chance to do some things I couldn't do before. ptgic_7	<input type="checkbox"/>	88/Refused				
8. My faith (belief) in God is stronger than it was before. ptgic_8	<input type="checkbox"/>	88/Refused				
9. I have learned that I can deal with more things than I thought I could before. ptgic_9	<input type="checkbox"/>	88/Refused				
10. I have new ideas about how I want things to be when I grow up. ptgic_10	<input type="checkbox"/>	88/Refused				

PTGI Child Version Total Score Variable: ptgictot

DEMOGRAPHICS

Next I have some general questions about you. This is the last section of the survey.

Interviewer instructions: Record participant’s weight and height in pounds and feet/inches. Enter into database in kg and cm

1. What is your current weight? (lbs) htfu (code 9999 for unknown)

Added to adult data collection in 2015

2. What is your current height? (feet/inches) wtfu (code 9999 for unknown)

Added to adult data collection in 2015

3. Where are you currently living? (Choose only one) resdencfu

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

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.

4. What is your current zip code? zipfu

(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

5. Who are you currently living with? (Choose all that apply)

Interviewer instructions: Probe if needed to make sure that all people participant is living with are accounted for in their answer.

- 4. Parent or step-parent livingafu__4
- 5. Other relative (siblings, grandparents) livingafu__5
- 6. Others, not part of family livingafu__6
- 7. Guardian livingafu__7
- 88. Declined to answer/Refused
- 99. Unknown

0 = not checked
1 = checked

6. What is your current school status? aschoolfu

- 1. In School (*Interviewer Instructions: Continue with #7 below if this is a 6, 12, or 24 month follow-up. Skip to #10 on the next page if this is a 5, 10, or 15 year follow-up.*)
- 2. Not in School (*Interviewer Instructions: Skip to #8 below*)
- 99. Unknown

Interviewer Instructions: If in school and this is a 6, 12, Or 24 month follow-up, ask...

7. ...is it the same program or a new program as compared with your last interview? (Or, as compared with before your burn injury, if this is a 6 month follow-up). aprogrfu

Interviewer Instructions: Ask as open ended question and probe about part or full time school status.

- 1. Same program full time
- 2. Same program part time
- 3. New program full time
- 4. New program part time
- 5. Did not resume school
- 88. Declined to answer/Refused
- 99. Unknown

- 6. Returned to individual program, home school
- 7. Not in school

Interviewer instructions: Skip #8 and move on to #10, below, if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.

8. What was your first date to return to school since the injury? (Please take your best guess if you don't know the exact date) :____/____/____

Entered into the patient status form: returndat

Interviewer Instructions: Skip to #10 on the next page if the participant is going to school.

9. If you aren't going to school, why not? **whynotfu**

- 1. Burn related
- 2. Other medical problems
- 4. Emotional/social
- 5. Legal/jail
- 6. Substance abuse
- 7. Personal choice
- 8. Other
- 77. Not applicable (going to school)
- 88. Declined to answer/Refused
- 99. Unknown

10. How many years of education have you completed? (*Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, "If you have not graduated from high school, please indicate the number of years spent in school."*) *If participant tries to count years rather than degree attained, use the prompt, "In other words, what is the highest level of education you have completed?"*). **educfup**

Interviewer Instructions: Ask the question as open-ended, and then mark the appropriate response.

- 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
- 66. Other
- 88. Declined to answer/Refused
- 99. Unknown

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

- 1. I am not receiving disability income (*Interviewer Instructions: skip to #13 if the participant is not receiving disability income*)
- 2. Social Security Disability
- 88. Declined to answer/Refused
- 99. Unknown

- 3. Private long term insurance disability income
- 4. Supplemental security income (SSI)
- 5. Worker's compensation
- 6. Other disincfupo

Interviewer Instructions: If the participant is receiving disability income, continue with #12

12. 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. Unknown

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

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

14. Do you currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimpfup**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: _____

Follow-up Information: *Interviewer instructions: Fill this page out before beginning the interview with the participant.*

Who is filling out this questionnaire? (Select all that apply)

- 1. Mother or stepmother proxy__1 proxy__77, not applicable (not proxy)
- 2. Father or stepfather proxy__2
- 3. Guardian proxy__3
- 4. Other proxy__4

1. Follow-up period follow_up

- 1. 6-month follow-up
- 2. 12 month follow-up
- 3. 24 month follow-up
- 4. 5 year follow-up

Previous variable was called "followup". For this new variable, additional time-points have been added. In the previous iteration, "followup", 4-Other.

2. What is the method of administration of this form? admin_fup

- 1. In person
- 2. Mail
- 3. Telephone interview
- 4. Online
- 5. Medical record review

Previous variable was called "admin_2". For this new variable, additional options have been added — Online and Medical record review.

3. What is the language of administration of this form? language_fup

- 1. English
- 2. Spanish
- 3. Other

Previous variable was called "admin_2".

4. What is the status of this follow-up assessment? (Choose only one) lostfolo

- 1. Some or all assessment done
- 2. Death due to burn related complications
- 3. Death due to non-burn related complications
- 4. Unable to locate
- 5. Refused this assessment
- 6. Unable to test/med comp/incapable of responding
- 7. Failed to respond
- 8. Did not consent to future assessment/withdrew
- 11. Incarcerated
- 13. Still in hospital (not discharged yet)
- 14. Unable to travel for assessment

Interviewer Instructions: Update date and cause of death on Patient Status Form

Option 14 added with new forms in 2015

15. Death (unknown causes) (*Interviewer Instructions: Update date and cause of death on Patient Status Form*) **Option 15 added with new forms in 2018**

Interviewer Instructions: *Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. Have the updated Patient Status form with you to help with the interview.*

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) next to that item.

Replace the introduction script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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

Thank you for continuing to participate in our study of young people with burn injuries. Like our previous interviews, I'll be asking questions about your child's burn injury and other questions about him/her and people around him/her. Your answers will help us understand the experiences of all people with burn injury. 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 your child best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Burn Injury Follow-up

First I have some questions related to your child’s burn injury...

1. Since your last interview, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? *Interviewer Instructions: The parent can choose N/A if their child is under the age of 5 or too young to discuss problems with other burn survivors.* **peersupprx**

- 1. Yes
- 2. No
- 77. Not applicable
- 99. Don’t know
- 88. Declined to answer/Refused
- 99. Unknown

2. Since the last interview, has your child received any of the following services at home or outpatient? (Choose all that apply)

If clarification needed: 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.

- 1. No services (*Interviewer Instructions: skip to #6, surgery item, on the next page*) **servicesprx__1**
 - 2. Occupational therapy **servicesprx__2**
 - 3. Physical therapy **servicesprx__3**
 - 4. Speech language pathology **servicesprx__4**
 - 5. Social work **servicesprx__5**
 - 6. Psychological services **servicesprx__6**
 - 7. Vocational services or child life services **servicesprx__7**
 - 88. Declined to answer/Refused **servicesprx__88**
 - 99. Unknown **servicesprx__99**
- 0 = not checked
1 = checked

Added in 2015

Interviewer Instructions: if parent indicates that services were received but that those services were not occupational and/or physical therapy, skip to #6, surgery item, on the next page.

Interviewer Instructions: Continue with these questions if the child received OT and/or PT...

3. How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? **numtherprx**

- 1. One
- 2. 2-4
- 3. 5-10
- 4. More than 10
- 77. No PT/OT (*skip to #6, surgery item, on the next page*)

Since your last interview, where did your child receive his/her outpatient occupational or physical burn therapy?

- 4. This clinical burn center? **ther_brn_ctrprx**
- 1. Yes
- 2. No
- 77. Not applicable (no OT/PT received)
- 88. Declined to answer/Refused
- 99. Unknown

5. Other facility? **ther_otrprx**

1. Yes

2. No

77. Not applicable (no OT/PT received)

88. Declined to answer/Refused

99. Unknown

6. Since your last interview [*provide date*], has your child had any burn related surgeries (such as surgeries for open wounds or scar management)? **surgery_fuprx**

1. Yes

2. No (*Interviewer Instructions: skip to Child Health Conditions, below*)

99. Don't know (*Interviewer Instructions: skip to Child Health Conditions, below*)

88. Declined to answer/Refused

Parentetical statement (such as surgeries for open wounds or scar management) added to variable with new Forms in 2018

Interviewer Instructions: Continue with this question if the participant had burn related surgeries

7. Has your child had any burn-related surgeries outside of [*name the BMS center*]? **surgoutprx**

1. Yes

2. No (*Interviewer Instructions: skip to Child Health Conditions, below*)

99. Don't know (*Interviewer Instructions: skip to Child Health Conditions, below*)

88. Declined to answer/Refused

Child Health Conditions

Interviewer instructions: Each question below is answered "yes" or "no".

If answered "yes", then ask "To what extent does this problem affect your child's daily activities?"

Responses for this question are:

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>
------------------------	------------------------------------	-------------------------------	----------------------------------	--------------------------------------	-------------------------------	------------------------------------

Children's development can be affected by the health problems that they experience. I will be asking you some questions about different health problems. I need to know whether or not your child has any of these problems. If your child has a health problem, I will be asking you to what extent the health problem affects your child's daily activities.

Does your child have problems...	Problem?	1	2	3	4	5	6	7
1. Seeing? chcprox1, chcprox1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						

88 / 99

88 / 99

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99							
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99							
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99							
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>	88 / 99							
Does your child have problems...	Problem?	1	2	3	4	5	6	7		
13. with Repeated infections? chcprox13, chcprox13a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								
14. with Breathing (eg asthma)? chcprox14, chcprox14a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								
17. with the Heart (such as a birth defect)? chcprox17, chcprox17a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								
18. with Pain? chcprox18, chcprox18a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>								

19. Does your child have any other health problems? **chcprox19** Yes No
If yes, specify problem: **chcprox19ot** (text field)

88. Declined to answer/Refused
99. Unknown

Pain and Itch

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

	0= Not At All	1=A little bit	2=Some -what	3=Quite a bit	4=Very much
1. Pain bmspain	<input type="checkbox"/>				
2. Itching bmsitch	<input type="checkbox"/>				

Pain Medication

1. In the **past month** did your child take prescription medication for pain on a regular basis?
pmedprx

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

2. In the **past month** did your child take prescription medication for itch on a regular basis?
imedprx

1. Yes 88. Declined to answer/Refused
2. No 99. Unknown

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

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

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

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

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

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

Previous variable, **psych**, used this wording:

FT27. Since your last follow-up, have you received psychological or peer support therapy for your burn? New variables, splitting **psych** into two questions, added in 2015

DEMOGRAPHICS

Next I have some general questions about your child.

Interviewer instructions: Record participant's weight and height in pounds and feet/inches and enter into the database in kg and cm

1. What is your child's current weight? (lbs) wtfuprx (code 9999 for unknown)

2. What is your child's current height? (feet/inches) htfuprx (code 9999 for unknown)

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

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.

4. What is your child's current zip code? zipfuprx
(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

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

Interviewer instructions: Probe if needed to make sure that all people child is living with are accounted for in the answer.

- 4. Parent or step-parent **livingafu__4**
 - 5. Other relative (siblings, grandparents) **livingafu__5**
 - 6. Others, not part of family **livingafu__6**
 - 7. Guardian **livingafu__7**
 - 88. Declined to answer/Refused **livingafu__88**
 - 99. Unknown **livingafu__99**
- 0 = not checked
1 = checked

6. What is your child's current school status? **aschoolfuprx**

- 1. In School (*Interviewer Instructions: Continue with #7 below if this is a 6, 12, or 24 month follow-up. Skip to #9 on the next page if this is a 5, 10, or 15 year follow-up.*)
- 2. Not in School (*Interviewer Instructions: Skip to #9 on the next page*)
- 99. Unknown

Interviewer Instructions: If in school and this is a 6, 12, Or 24 month follow-up, ask...

7. ...is it the same program or a new program as compared with your last interview? (Or, as compared with before his/her burn injury, if this is a 6 month follow-up). **aprogfuprx**

Interviewer Instructions: Ask as open ended question and probe about part or full time school status.

- 1. Same program full time
- 2. Same program part time
- 3. New program full time
- 4. New program part time
- 5. Did not resume school
- 6. Returned to individual program, home school
- 7. Not in school
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer instructions: Skip #8 and move on to #9 if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.

8. What was your child's first date to return to school since the injury? (Please take your best guess if you don't know the exact date) :____/____/____ **retrndat**

Found in patient status form

Interviewer Instructions: Skip to #10, below, if the child is going to school.

9. If your child isn't going to school, why not? **whynotfuprx**

- 0. Not school age
- 1. Burn related
- 2. Other medical problems
- 4. Emotional/social
- 5. Legal/jail
- 6. Substance abuse
- 7. Personal choice
- 8. Other
- 77. Not applicable (going to school)
- 88. Declined to answer/Refused
- 99. Unknown

10. How many years of education has your child completed? (*Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, "If your child has not graduated from high school, please indicate the number of years spent in school."*) *If participant tries to count years rather than degree attained, use the prompt, "In other words, what is the highest level of education your child has completed?"*).

Interviewer Instructions: Ask the question as open-ended, then mark the appropriate response below.

educfuprx

- 0. Preschool completed
- 88. Declined to answer/Refused
- 99. Unknown

- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 77. Not applicable (child is too young for school)

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

- 1. My child is not receiving disability income (*Interviewer Instructions: skip to #13 on the next page if the child is not receiving disability income*)
- 2. Social Security Disability
- 4. Supplemental security income (SSI)
- 6. Other **disincfupprx**
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer Instructions: If the child is receiving disability income, continue with #12

12. If yes, is your child receiving disability income due to his/her burn injury? **disincbrnprx**

- 1. Yes, my child is receiving disability income due to his/her burn injury
- 2. No, my child is not receiving disability income due to his/her burn injury
- 77. Not applicable (not receiving disability income)
- 99. Unknown

13. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? **physprobupprx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

14. Does your child currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimpfupprx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

15. Approximately what was your household's total income for the last full year (total income of all members of the household)?

If clarification is needed, say, "Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds."

If clarification about currency is needed, say, "these categories are in U.S. dollar amounts."

hinccatfupprx

- 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
- 88. Declined to answer/Refused
- 99. Unknown

- 6. \$200,000 or more
- 7. Living outside the United States
- 77. Not applicable (e.g., living in an institution)

16. How many people are in your household? numhsfupprx
(Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

17. 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

- 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)
- 88. Declined to answer/Refused
- 99. Unknown

Notes: 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.

Body Image

The following questions ask about this child’s appearance:

	Definitely true=1	Mostly true=2	Not sure=3	Mostly false=4	Definitely false=5	
1. This child feels that the burn is unattractive to others. <u>bodyimp_1</u>	<input type="checkbox"/>	88 / 99				
2. This child thinks that people would not want to touch him/her. <u>bodyimp_2</u>	<input type="checkbox"/>	88 / 99				
3. This child feels unsure of himself/herself among strangers. <u>bodyimp_3</u>	<input type="checkbox"/>	88 / 99				
4. Changes in this child’s appearance have interfered with his/her relationships. <u>bodyimp_4</u>	<input type="checkbox"/>	88 / 99				

PEDI Mobility

Total Body Image Proxy Score: bodyim_tot_proxy

I will read you 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.)

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric Proxy 0-7 Interview Form II
NewMSID_____

	Unable=1	Hard=2	A little hard=3	Easy=4	
2. When lying on belly, turns head to both sides pedi_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Sits on floor without support of pillow or couch pedi_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Walks while holding onto furniture or walls pedi_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. Walks outdoors on grass, mulch or gravel pedi_6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. When running, is able to go around people and objects pedi_7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

PEDI Total Score: **pedi_tot**

Interviewer instructions: *If the child is younger than 3, ask the question below and then you are finished with the interview. If the child is between the ages of 3 and 7, continue with the rest of the survey on the next page.*

Indicate time survey ended: _____

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!

Interviewer instructions: *If the child is between the ages of 3 and 7, continue with the rest of the survey.*

NIH Toolbox Anger (for children ages 3-7)

Please indicate how often or true the behavior is of your child.	0=Never or not true	1=Sometimes or somewhat true	2=Often or very true	
1. Has temper tantrums or hot temper. pedproxang01	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Argues a lot with adults. pedproxang02	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Is easily annoyed by others pedproxang06	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Gets back at people pedproxang08	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

NIH Toolbox Anger Proxy 3-7 T-Score: **tbangscore_proxy**

NIH Toolbox Sadness (for children ages 3-7)

Please indicate how often or true the behavior is of your child.	0=Never or not true	1=Sometimes or somewhat true	2=Often or very true	
1. Is unhappy, sad or depressed. <i>pedproxdep03</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Cries a lot. <i>pedproxdep05</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Seems lonely. <i>pedproxdep06</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Withdraws from peer activities. <i>pedproxdep13</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

NIH Toolbox Sadness Proxy 3-7 T-Score: *tbsadtscore_proxy*

NIH Toolbox General Life Satisfaction (for children ages 3-7)

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

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!

Indicate time survey ended: _____

Today's Date: ____ / ____ / ____

(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: _____

Follow-up Information: *Interviewer instructions: Fill this page out before beginning the interview with the participant.*

Who is filling out this questionnaire? (Select all that apply)

- 1. Mother or stepmother proxy__1
- 2. Father or stepfather proxy__2 proxy__77, not applicable (not proxy)
- 3. Guardian proxy__3
- 4. Other proxy__4

1. Follow-up period follow_up

- 1. 6-month follow-up
- 2. 12-month follow-up
- 3. 24-month follow-up
- 4. 5 year follow-up
- 5. 10 year follow-up
- 6. 15 year follow-up

Previous variable was called "followup". For this new variable, additional time-points have been added. In the previous iteration, "followup", 4-Other.

2. What is the method of administration of this form? admin_fup

- 1. In person
- 2. Mail
- 3. Telephone interview
- 4. Online
- 5. Medical record review

Previous variable was called "admin_2". For this new variable, additional options have been added — Online and Medical record review.

3. What is the language of administration of this form? language_fup

- 1. English
- 2. Spanish
- 3. Other

Previous variable was called "admin_2".

4. What is the status of this follow-up assessment? (Choose only one) lostfolo

- 1. Some or all assessment done
- 2. Death due to burn related complications
- 3. Death due to non-burn related complications
- 4. Unable to locate
- 5. Refused this assessment
- 6. Unable to test/med comp/incapable of responding
- 7. Failed to respond
- 8. Did not consent to future assessment/withdrew
- 11. Incarcerated
- 13. Still in hospital (not discharged yet)

Interviewer Instructions: Update date and cause of death on Patient Status Form

- 14. Unable to travel for assessment **Option 14 added with new forms in 2015**
- 15. Death (unknown causes) (*Interviewer Instructions: Update date and cause of death on Patient Status Form*) **Option 15 added with new forms in 2018**

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. 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. Have the updated Patient Status form with you to help with the interview.

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) next to that item.

Replace the introduction script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

Introduction script:

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

Thank you for continuing to participate in our study of young people with burn injuries. Like our previous interviews, I'll be asking questions about your child's burn injury and other questions about him/her and people around him/her. Your answers will help us understand the experiences of all people with burn injury. 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 your child best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering. Just tell me, "skip."

We're going to get started with the survey. Please let me know at any time if you have any questions.

Burn Injury Follow-up

First I have some questions related to your child's burn injury...

1. Since your last interview, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? **peersupprx** 88. Declined to answer/Refused
1. Yes 99. Unknown
2. No

2. Since the last interview, has your child received any of the following services at home or outpatient? (Choose all that apply)

If clarification needed:

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.

1. No services (*Interviewer Instructions: skip to #6, surgery item, on the next page*)
servicesprx__1 88. Declined to answer/Refused
2. Occupational therapy **servicesprx__2** 99. Unknown
3. Physical therapy **servicesprx__3**
4. Speech language pathology **servicesprx__4** 0 = not checked
5. Social work **servicesprx__5** 1 = checked
6. Psychological services **servicesprx__6**
7. Vocational services or child life services **servicesprx__7**

Interviewer Instructions: if parent indicates that services were received but that those services were not occupational and/or physical therapy, skip to #6, surgery item, on the next page.

Interviewer Instructions: Continue with these questions if the child received OT and/or PT...

3. How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? **numtherprx** 88. Declined to answer/Refused
1. One 99. Unknown
2. 2-4
3. 5-10
4. More than 10
77. No OT/PT (*Interviewer Instructions: skip to #6, surgery item, on the next page*)

Since your last interview, where did your child receive his/her outpatient occupational or physical burn therapy?

4. This clinical burn center? **ther_brn_ctrprx** 88. Declined to answer/Refused
1. Yes 99. Unknown
2. No
77. Not applicable (no OT/PT received)
5. Other facility? **ther_otrprx** 88. Declined to answer/Refused
1. Yes 99. Unknown
2. No
77. Not applicable (no OT/PT received)

6. Since your last interview [*provide date*], has your child had any burn related surgeries (such as surgeries for open wounds or scar management)? **surgery_fuprx**

1. Yes
 2. No (*Interviewer Instructions: skip to Child Health Conditions, below*)
 99. Don't know (*Interviewer Instructions: skip to Child Health Conditions, below*)
 88. Declined to answer/Refused

Parentetical statement (such as surgeries for open wounds or scar management) added to variable with new Forms in 2018

Interviewer Instructions: Continue with this question if the participant had burn related surgeries

7. Has your child had any burn-related surgeries outside of [*name the BMS center*]?

surgoutprx

1. Yes
 2. No
 99. Don't know
 88. Declined to answer/Refused

Child Health Conditions

Interviewer instructions: Each question below is answered “yes” or “no”.

If answered “yes”, then ask “To what extent does this problem affect your child’s daily activities?”

Responses for this question are:

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
-----------------	-----------------------------	------------------------	---------------------------	-------------------------------	------------------------	-----------------------------

Children’s development can be affected by the health problems that they experience. I will be asking you some questions about different health problems. I need to know whether or not your child has any of these problems. If your child has a health problem, I will be asking you to what extent the health problem affects your child’s daily activities.

Does your child have problems...	Problem?	1	2	3	4	5	6	7
1. Seeing? chcprox1, chcprox1a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>						

8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
13. with Repeated infections? chcprox13, chcprox13a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
14. with Breathing (eg asthma)? chcprox14, chcprox14a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
17. with the Heart (such as a birth defect)? chcprox17, chcprox17a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							
18. with Pain? chcprox18, chcprox18a	<input type="checkbox"/> 1Yes <input type="checkbox"/> 0No	<input type="checkbox"/>							

19. Does your child have any other health problems? **chcprox19** Yes No
 If yes, specify problem: **chcprox19ot (text field)** 88. Declined to answer/Refused
 99. Unknown

Pain Medication

1. In the **past month** did your child take prescription medication for pain on a regular basis?
pmedproxfup

1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

2. In the **past month** did your child take prescription medication for itch on a regular basis?
imedproxfup

1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

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

1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

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

1. Yes 88. Declined to answer/Refused
 2. No 99. Unknown

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

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

- 1. Yes
- 2. No

- 88. Declined to answer/Refused
- 99. Unknown

Body Image

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

Body Image Self-Report Total: **bodyim_tot_self**

PROMIS-Anger

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. My child felt mad pf1anger1	<input type="checkbox"/>	88 / 99				
2. My child was so angry he/she felt like yelling at somebody pf1anger5	<input type="checkbox"/>	88 / 99				
3. My child was so angry he/she felt like throwing something pf1anger3	<input type="checkbox"/>	88 / 99				
4. My child felt upset pf1anger10	<input type="checkbox"/>	88 / 99				
5. When my child got mad, he/she stayed mad pf1anger8	<input type="checkbox"/>	88 / 99				

PROMIS Anger Proxy: **angtscore_proxy**

PROMIS-Depressive Symptoms

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4= Almost always	
1. My child could not stop feeling sad pf2depr7	<input type="checkbox"/>	88 / 99				
2. My child felt everything in his/her life went wrong pf1depr7	<input type="checkbox"/>	88 / 99				

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric Proxy 8-17 Interview Form II
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3. My child felt like he/she couldn't do anything right pf1depr5	<input type="checkbox"/>	88 / 99				
4. My child felt lonely pf2depr10	<input type="checkbox"/>	88 / 99				
5. My child felt sad pf2depr3	<input type="checkbox"/>	88 / 99				
6. My child thought that his/her life was bad pf2depr5	<input type="checkbox"/>	88 / 99				

PROMIS Depressive Symptoms T-Score Variable: deptscore_proxy

PROMIS-Pain Interference

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. My child had trouble sleeping when he/she had pain pf2pain5	<input type="checkbox"/>	88 / 99				
2. My child felt angry when he/she had pain pf3pain7	<input type="checkbox"/>	88 / 99				
3. My child had trouble doing schoolwork when he/she had pain pf2pain2	<input type="checkbox"/>	88 / 99				
4. It was hard for my child to pay attention when he/she had pain pf3pain2	<input type="checkbox"/>	88 / 99				
5. It was hard for my child to run when he/she had pain pf2pain4	<input type="checkbox"/>	88 / 99				
6. It was hard for my child to walk one block when he/she had pain pf1pain4	<input type="checkbox"/>	88 / 99				
7. It was hard for my child to have fun when he/she had pain pf3pain4	<input type="checkbox"/>	88 / 99				
8. It was hard for my child to stand when he/she had pain pf4pain6	<input type="checkbox"/>	88 / 99				

PROMIS Pain Interference T-Score: painintscore_proxy

PROMIS-Peer Relationships

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. My child felt accepted by other kids his/her age pf3socabil9	<input type="checkbox"/>	88 / 99				
2. My child was able to count on his/her friends pf4socabil12	<input type="checkbox"/>	88 / 99				
3. My child was good at making friends pf3socabil4	<input type="checkbox"/>	88 / 99				
4. My child and his/her friends helped each other out pf3socrole4	<input type="checkbox"/>	88 / 99				
5. Other kids wanted to be my child's friend pf1socabil2	<input type="checkbox"/>	88 / 99				

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

6. Other kids wanted to be with my child pf3socrole4	<input type="checkbox"/>	88 / 99				
7. Other kids wanted to talk to my child pf2socabil9	<input type="checkbox"/>	88 / 99				

PROMIS Peer Relationships T-Score: peertscore_proxy

PROMIS-Physical function mobility

In the past 7 days...	0=with no trouble	1=with a little trouble	2= With some trouble	3= With a lot of trouble	4=Not able to do	
1. My child could do sports and exercise that other kids his/her age could do pf1mobil3	<input type="checkbox"/>	88 / 99				
2. My child could get up from the floor pf3mobil9	<input type="checkbox"/>	88 / 99				
3. My child could keep up when he/she played with other kids pf4mobil4	<input type="checkbox"/>	88 / 99				
4. My child could move his/her legs pf3mobil8	<input type="checkbox"/>	88 / 99				
5. My child could stand up without help pf3mobil3	<input type="checkbox"/>	88 / 99				
6. My child could stand up on his/her tiptoes pf2mobil7	<input type="checkbox"/>	88 / 99				
7. My child could walk up stairs without holding on to anything pf2mobil4	<input type="checkbox"/>	88 / 99				
8. My child has been physically able to do the activities he/she enjoys most pf1mobil1	<input type="checkbox"/>	88 / 99				

PROMIS Physical Function Mobility T-Score: pfmobtscore_proxy

PROMIS-Physical function Upper Extremity

In the past 7 days...	0=with no trouble	1=with a little trouble	2= With some trouble	3= With a lot of trouble	4=Not able to do	
1. My child could button his/her shirt or pants pf2uprext3	<input type="checkbox"/>	88 / 99				
2. My child could open a jar by himself/herself pf4uprext1	<input type="checkbox"/>	88 / 99				
3. My child could open the rings in school binders pf3uprext11	<input type="checkbox"/>	88 / 99				
4. My child could pour a drink from a	<input type="checkbox"/>	88 / 99				

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

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full pitcher pf4uprext10						
5. My child could pull a shirt on over his/her head without help pf3uprext4	<input type="checkbox"/>	88 / 99				
6. My child could pull open heavy doors pf3uprext9	<input type="checkbox"/>	88 / 99				
7. My child could put on his/her shoes without help pf2uprext2	<input type="checkbox"/>	88 / 99				
8. My child could use a key to unlock a door pf3uprext7	<input type="checkbox"/>	88 / 99				

PROMIS Upper Extremity T-Score: **pfuptscore_proxy**

NIH Toolbox General Life Satisfaction

Indicate how much you agree or disagree:	1= Strongly disagree	2= Disagree	3= Neither agree nor disagree	4= Agree	5= Strongly agree	
1. My child's life is going well. papxy066	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My child's life is just right. papxy067	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. My child has a good life. papxy070	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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"/>	88 / 99

BMS-Itch (modified for BMS based on the PROMIS Pain interference)

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. My child had trouble sleeping when he/she was itching bmsitchp_1	<input type="checkbox"/>	88 / 99				
2. My child felt angry when he/she was itching bmsitchp_2	<input type="checkbox"/>	88 / 99				
3. My child had trouble doing schoolwork when he/she was itching bmsitchp_3	<input type="checkbox"/>	88 / 99				
4. It was hard for my child to pay attention when he/she was itching bmsitchp_4	<input type="checkbox"/>	88 / 99				
5. It was hard for my child to have fun when he/she was itching bmsitchp_5	<input type="checkbox"/>	88 / 99				

DEMOGRAPHICS

Next I have some general questions about your child.

Interviewer instructions: Record participant's weight and height in pounds and feet/inches and enter it into the database in kg and cm

- 1. What is your child's current weight? (lbs) wtfuprx (code 9999 for unknown)
- 2. What is your child's current height? (feet/inches) htfuprx (code 9999 for unknown)
- 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

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.

2018

- 4. What is your child's current zip code? zipfuprx
(Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

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

Interviewer instructions: Probe if needed to make sure that all people child is living with are accounted for in the answer.

- 4. Parent or step-parent **livingafu__4**
 - 5. Other relative (siblings, grandparents) **livingafu__5**
 - 6. Others, not part of family **livingafu__6**
 - 7. Guardian **livingafu__7**
 - 88. Declined to answer/Refused **livingafu__88**
 - 99. Unknown **livingafu__99**
- 0 = not checked
1 = checked

- 6. What is your child's current school status? **aschoolfuprx**

- 1. In School (*Interviewer Instructions: Continue with #7 if this is a 6, 12, or 24 month follow-up. Skip to #10, on the next page, if this is a 5, 10, or 15 year follow-up.*)
- 2. Not in School (*Interviewer Instructions: Skip to #9 on the bottom of this page*)
- 99. Unknown

Interviewer Instructions: If in school and this is a 6, 12, Or 24 month follow-up, ask...

- 7. ...is it the same program or a new program as compared with your last interview? (Or, as compared with before his/her burn injury, if this is a 6 month follow-up). **aprogfuprx**

Interviewer Instructions: Ask as open ended question and probe about part or full time school status.

- 1. Same program full time
- 2. Same program part time
- 3. New program full time
- 4. New program part time
- 5. Did not resume school
- 6. Returned to individual program, home school
- 88. Declined to answer/Refused
- 99. Unknown

7. Not in school

Interviewer instructions: Skip #8 and move on to #10 on the next page if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.

8. What was your child's first date to return to school since the injury? (Please take your best guess if you don't know the exact date) :____/____/____ **retrndat**

Found in patient status form

Interviewer Instructions: Skip to #10 on the next page if the child is going to school.

9. If your child isn't going to school, why not? **whynotfuprx**

- | | |
|---|---|
| 1. <input type="checkbox"/> Burn related | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Other medical problems | 99. <input type="checkbox"/> Unknown |
| 4. <input type="checkbox"/> Emotional/social | |
| 5. <input type="checkbox"/> Legal/jail | |
| 6. <input type="checkbox"/> Substance abuse | |
| 7. <input type="checkbox"/> Personal choice | |
| 8. <input type="checkbox"/> Other | |
| 77. <input type="checkbox"/> Not applicable (going to school) | |

10. How many years of education has your child completed? (*Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, "If your child has not graduated from high school, please indicate the number of years spent in school."*) *If participant tries to count years rather than degree attained, use the prompt, "In other words, what is the highest level of education your child has completed?"*). **educfuprx**

Interviewer Instructions: Ask the question as open-ended, then mark the appropriate response below.

- | | |
|---|---|
| 1. <input type="checkbox"/> 1 year or less | |
| 2. <input type="checkbox"/> 2 years | 88. <input type="checkbox"/> Declined to answer/Refused |
| 3. <input type="checkbox"/> 3 years | 99. <input type="checkbox"/> Unknown |
| 4. <input type="checkbox"/> 4 years | |
| 5. <input type="checkbox"/> 5 years | |
| 6. <input type="checkbox"/> 6 years | |
| 7. <input type="checkbox"/> 7 years | |
| 8. <input type="checkbox"/> 8 years | |
| 9. <input type="checkbox"/> 9 years | |
| 10. <input type="checkbox"/> 10 years | |
| 11. <input type="checkbox"/> 11 or 12 years; no diploma | |
| 12. <input type="checkbox"/> High school diploma | |
| 66. <input type="checkbox"/> Other | |

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

- | | |
|--|---|
| 1. <input type="checkbox"/> My child is not receiving disability income (<i>Interviewer Instructions: skip to #13, below, if the child is not receiving disability income</i>) | |
| 2. <input type="checkbox"/> Social Security Disability | 88. <input type="checkbox"/> Declined to answer/Refused |
| 3. <input type="checkbox"/> Private long term insurance disability income | 99. <input type="checkbox"/> Unknown |

- 4. Supplemental security income (SSI)
- 5. Worker's compensation
- 6. Other disincfupoprx

Interviewer Instructions: If the child is receiving disability income, continue with #12

12. If yes, is your child receiving disability income due to his/her burn injury? **disincbrnprx**
- 1. Yes, my child is receiving disability income due to his/her burn injury
 - 2. No, my child is not receiving disability income due to his/her burn injury
 - 77. Not applicable (not receiving disability income)
 - 99. Unknown

13. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? **physprobfulprx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

14. Does your child currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimpfulprx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

15. Approximately what was your household's total income for the last full year (total income of all members of the household)?

If clarification is needed about the reason this question is asked, say, "Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds." **hinccatfulprx**

If clarification about currency is needed, say, "these categories are in U.S. dollar amounts."

- 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. Declined to answer/Refused
- 99. Unknown

16. How many people are in your household? numhsfulprx

(Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

17. 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**

- 1. Medicare
- 2. Medicaid (DSHS)
- 3. Private insurance/HMO/PPO/Pre-paid/Managed
- 4. Worker's compensation (L&I)
- 6. Champus/Tri-Care
- 88. Declined to answer/Refused
- 99. Unknown

- 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)

Interviewer Instructions: *If the child is younger than 14, ask the question below and then you are finished with the interview. If the child is 14 or older, continue with the CIQ, on the last page.*

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!
Indicate time survey ended: _____

Interviewer instructions: *If the child is 14 or older, administer the CIQ, below.*

CIQ:

Currently:

1: Does your child take personal responsibility for grooming when asked? **cip2prx**

- 1. Often
- 2. Sometimes
- 3. Never
- 88. Declined to answer/Refused
- 99. Unknown

Approximately how many times a month does your child usually participate in the following activities outside of your home?

2: Shopping **ci3prx**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times
- 88. Declined to answer/Refused
- 99. Unknown

3: Leisure activities such as movies, sports, and restaurants. **ci4prx**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times
- 88. Declined to answer/Refused
- 99. Unknown

4: Visiting friends or relatives **ci5prx**

- 1. Never
- 2. 1-4 times
- 3. 5 or more times
- 88. Declined to answer/Refused
- 99. Unknown

Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric Proxy 8-17 Interview Form II
NewMSID_____

5: When your child participates in leisure activities does he/she usually do this alone or with others? **ci6prx**

- 1. Mostly alone
- 2. Mostly with friends who have burn injuries
- 3. Mostly with family members
- 4. Mostly with friends who do not have burn injuries
- 5. With a combination of family and friends
- 77. Not applicable (no leisure activities)
- 88. Declined to answer/Refused
- 99. Unknown

6: Do your child have a best friend with whom he/she can confide? **ci7prx**

- 1. Yes
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

CIQ Social Integration Score Proxy: ciqsicprx

Is there anything else you would like to tell us? _____

We're done with the survey. Thank you very much for your participation in this research study!

Indicate time survey ended: _____