

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 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/ wnd closure surgery
- 5. Hand, face, feet burn w/ wound closure surgery
- 6. Criteria prior to 8/1/2005

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, skip to PS5)
- 3. No, did not consent/missed (do not collect DOB, skip to PS5)

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 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. What is your race and/or ethnicity?". If it is not appropriate, gather the information by medical record.*)

Obtaining ethnicity data from people who do not consent was added with new Forms in 2015.

Previous variable was ethnicity

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

b. Ethnicity? **ethnicity**

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

Source of PS9: **src_ethnicity**

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)
(code 1900/08/08 for not applicable)

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

disch_date _____ (yyyy/mm/dd) (code 1900/09/09 for unknown)

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

disch_date_2nd _____ (yyyy/mm/dd) (code 1900/08/08 for not applicable)

PS14. Date consent form signed by participant

cnsnt_date _____ (yyyy/mm/dd) (code 1900/09/09 for unknown)

Update follow-up information here:

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

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

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: **pretiol**

1. Fire/flare
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 (*if employment and recreation do not apply*)
3. Non-intentional recreation
4. Non-intentional non-specified (*if there is no information on circ. other than non-inten.*)
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

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
4. Worker's compensation (L&I)
5. HMO/PPO/Pre-paid/Managed Care
6. Champus/Tri-Care
7. Self-pay
8. Indigent (public support; charity care)
9. VA
10. Other
11. Philanthropy (private support)
99. Unknown

Notes:

- 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

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 with new Forms in 2015

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

1. Yes 2. No 99. Unknown

Notes:

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

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

2015

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) **trnkrft**

- 1 Yes 2. No 99. Unknown

Notes:

Parenthetical statement (back, chest, abdomen) added with new Forms in 2013

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

- 1 Yes 2. No 99. Unknown

Notes:

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

MR21. Shoulder/Upper Arm/Elbow **suegrft** (variable name prior to 10/13, with arm data, was **armgrft**)

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

MR22. Forearm (includes wrist) **farmgrft** (variable name prior to 10/13, 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**n_____ (XX.X)
(code 999 for unknown)

MR27. Total body surface area grafted (percent): **tbsagr**ft_____ (XX.X)
(code 0 for no grafting; code 999 for unknown)

MR28. Days on ventilator: **daysvent** _____ (code 0 for 0 days; 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

(previously collected variable was **contrctr**)

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

- 1 Yes 2. No 99. Unknown

NewMSID_____

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

1. Yes, above elbow right **amput1__1**; 0=not checked; 1=checked
2. Yes, above elbow left **amput1__2**; 0=not checked; 1=checked
3. Yes, above elbow bilateral **amput1__3**; 0=not checked; 1=checked
4. Yes, below elbow right **amput1__4**; 0=not checked; 1=checked
5. Yes, below elbow left **amput1__5**; 0=not checked; 1=checked
6. Yes, below elbow bilateral **amput1__6**; 0=not checked; 1=checked
7. Yes, digits only right **numdgr**____(fill in # of digits) (Thumb amputated? **thumb**
1-Yes 2-No, 99-Unknown) **amput1__7**; 0=not checked; 1=checked
8. Yes, digits only left **numdgtl**____(fill in # of digits) (Thumb amputated? **thumb**
 1-Yes 2-No, 99-Unknown) **amput1__8**; 0=not checked; 1=checked
9. Yes, digits only bilateral **numdgtb**____(fill in # of digits) (Thumbs amputated?
thumbb 1-Yes 2-No, 99-Unknown) **amput1__9**; 0=not checked; 1=checked
10. No **amput1__10**; 0=not checked; 1=checked
99. Unknown **amput1__99**; 0=not checked; 1=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**; 0=not checked; 1=checked
2. Yes, above knee left **amput2__2**; 0=not checked; 1=checked
3. Yes, above knee bilateral **amput2__3**; 0=not checked; 1=checked
4. Yes, below knee right **amput2__4**; 0=not checked; 1=checked
5. Yes, below knee left **amput2__5**; 0=not checked; 1=checked
6. Yes, below knee bilateral **amput2__6**; 0=not checked; 1=checked
7. Yes, digits only right **numldgr**____(fill in # of digits) **amput2__7**; 0=not
checked; 1=checked
8. Yes, digits only left **numldgtl**____(fill in # of digits) **amput2__8**; 0=not
checked; 1=checked
9. Yes, digits only bilateral **numldgtb**____(fill in # of digits) **amput2__9**; 0=not
checked; 1=checked
10. Transmetatarsal right (partial foot amputation right) **amput2__10**; 0=not checked;
1=checked
11. Transmetatarsal left (partial foot amputation left) **amput2__11**; 0=not checked;
1=checked
12. Transmetatarsal bilateral (partial foot amputation bilateral) **amput2__12**; 0=not
checked; 1=checked
13. No **amput2__13**; 0=not checked; 1=checked
99. Unknown **amput2__99**; 0=not checked; 1=checked

Notes:

New variable added with new Forms in 2015

NewMSID_____

MR35. Hand dominance **handdom**

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

Notes:

New variable added with new Forms in 2015

MR36. MRSA 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)

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

NewMSID_____

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_____

Medication Data Collection Table

New variable added with new Forms in December 2015

Name of Medication Prescribed at Discharge (add as many rows as necessary) (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: ____ / ____ / ____ **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 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; 0=not checked; 1=checked**
 2. Medical Record Abstraction Form **status__2; 0=not checked; 1=checked**
 3. Review of Systems Checklist Form **status__3; 0=not checked; 1=checked**
 4. 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.

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.

Answer Key:

If the interview is over the phone and the participant was sent an answer key, say, "Did you receive your answer key that we sent you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. If the participant was not sent an answer key, go to the second bullet below.

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- *If the answer is no, or if the participant was not sent an answer key, say "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- *If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

If the interview is in person and the participant has an answer key, say, "The answer key I gave you shows the responses you can choose from when you answer the questions I'll be asking. I will tell you when to use the answer key."

Let's get started. The first section is about your current health.

Health Status

1. Have you ever had another major injury requiring hospitalization besides your burn injury?
 1. Yes 88. Declined to answer/Refused **majhospdis**
 2. No 99. Unknown

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 (Pain Medication on page 5) 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 current health:	
1. Hearing loss? hlossdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
2. Change in voice? voicedis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
3. Vision problems not corrected by glasses or contact lenses? visiondis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
4. Eyelid problems? eyeliddis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
5. Excessive tearing of the eyes? teardis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
6. Difficulty with memory? memorydis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
7. Difficulty with thought processing? thoughtdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
8. Numbness, pins and needles or burning sensations in your burn scar? numbscdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
9. Numbness, pins and needles or burning sensations in your hands? numbhdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
10. Numbness, pins and needles or burning sensations in your feet? numbfdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
11. Trouble with your balance? tbalandis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99

12. Varicose veins? varveindis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
13. Swollen feet or legs? swflegdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
14. Swollen hands or arms? swharmdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
15. Difficulty breathing when doing your regular daily activities? difbrergdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
16. Difficulty breathing when exercising? difbreexdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
17. Skin cancer? skincandis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
18. Joint pain? jpaindis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
19. Have you ever been pregnant or fathered a child? preg_fathdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
20. Blood clots in legs or lungs? bclelungdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
21. Cold intolerance? cintoldis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
22. Excessive sweating? exsweatdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
23. Difficulty in hot environments? difhotdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99

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.

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

These questions added with new forms in December 2015.

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

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. **ci4_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 **ci5_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?

ci6_pre

- | | |
|---|---|
| 1. <input type="checkbox"/> Mostly alone | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Mostly with friends who have burn injuries (N/A for Form I) | 99. <input type="checkbox"/> Unknown |
| 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 | |

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

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

PHO-9 #9: PRE-BURN

Interviewer Instructions: Be informed of your center’s protocol for suicidal ideation, and follow those procedures if the participant chooses #3 or #4 (endorses suicidal ideation) with this item. If desired, indicate to the participant that this item is sensitive by saying, “The next question may be hard to answer or talk about.”

1. In the two weeks before your burn, how often were you bothered by thoughts that you would be better off dead or of hurting yourself in some way? **phq9_9_pre**

- 1. Not at all =0
- 2. Several days =1
- 3. More than half the days =2
- 4. Nearly every day =3
- 88. Declined to answer/Refused
- 99. Unknown

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 skip a question, circle the number 88 next to that question. If a response is missing, circle the number 99 next to that question (Unknown/missing).

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

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**

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

1

2

3

88/Refused
99/Unknown

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**

vr12pre3a

a. Accomplished less than you would like.

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**

vr12pre4a

a. Accomplished less than you would like.

1

2

3

4

5

88/Refused
99/Unknown

b. Didn't do work or other activities as **carefully** as usual. **vr12pre4b**

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:

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

	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	
vr12pre6a a. Did you feel calm and peaceful?	1	2	3	4	5	6	88/Refused 99/Unknown
b. Did you have a lot of energy? vr12pre6b	1	2	3	4	5	6	88/Refused 99/Unknown
c. Did you feel downhearted and blue? vr12pre6c	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

Pre-Injury Demographics

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

- 1. House
 - 2. Apartment
 - 3. Mobile home
 - 4. Institution
 - 5. Homeless
 - 6. Other
88. Declined to answer/Refused
99. Unknown

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?”

2. What was your zip code at the time of your burn injury? _____ **zip_pre**

(Code 99999 for unknown, code 00000 for Mexico)

Added to data collection forms in 2015.

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

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

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

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

Added to data collection forms in 2015.

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)?

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.”

hincatpre

- 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

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)

Added to data collection forms in 2015.

6. In the year prior to your burn injury, how many months did you work at a regular job? _____ *(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”) **mrjobpre**

- 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.

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

Occupation: _____ **occpre** _____

Code: _____ **occcodepre** _____

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

8. What was your employment status at the time of your burn? **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

Instructions: skip to #10, below

66-"Not working" on old forms

77-Not applicable due to age

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 fo the forms is now stred in the variable "employpre" as "66-not working on previous data collection "**

9. 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#10 and move on to #11 if the participant declined to answer the household income question or if the participant is a one person household (fill in income from household question if the participant is a one person household).

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

iinccatpre

- 1. Less than \$25,000
- 2. \$25,000-\$40,999
- 3. \$41,000-\$55,999
- 4. \$56,000-\$70,999
- 88. Declined to answer/Refused
- 99. Unknown

- 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)

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

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

- 1. In school
- 2. Not in school
- 88. Declined to answer/Refused
- 99. Unknown

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

Interviewer Instructions: Skip to #13, below, if participant was working or going to school before the burn injury.

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

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

13. 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

14. Before the burn, did you have any psychological issues, such as depression or anxiety? **psychis**

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

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

- 1. Yes
- 2. No
- 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.

PHQ-9 #9: DISCHARGE

Interviewer Instructions: Be informed of your center's protocol for suicidal ideation, and follow those procedures if the participant chooses #3 or #4 (endorses suicidal ideation) with this item. If desired, indicate to the participant that this item is sensitive by saying, "The next question may be hard to answer or talk about."

1. In the past 7 days, or since your burn if you were injured less than 7 days ago, how often have you been bothered by thoughts that you would be better off dead or of hurting yourself in some way? **phq9_9_dis**

- 1. Not at all =0
- 2. Several days =1
- 3. More than half the days =2
- 4. Nearly every day =3
- 88. Declined to answer/Refused
- 99. Unknown

Interviewer instructions: "Once" or "a few times" are not allowed responses to this item. If a participant volunteers this information, ask them to pick the best response out of the available response categories. If they do not want to pick the best response because they feel there is not an appropriate choice for their situation, code the response as "88".

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: DISCHARGE

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 is: **vr12dis1**

EXCELLENT	VERY GOOD	GOOD	FAIR	POOR
1	2	3	4	5

88/Refused
99/Unknown

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

BMS Adult Data Dictionary Form I
NewMSID _____

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?

**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? **vr12dis2a**

1 2 3 88/Refused
99/Unknown

b. Climbing **several** flights of stairs? **vr12dis2b**

1 2 3 88/Refused
99/Unknown

3. During the past 7 days, or since your burn if you were injured less than 7 days ago, have you had 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.**
vr12dis3a

1 2 3 4 5 88/Refused
99/Unknown

b. Were limited in the **kind** of work or other activities. **vr12dis3b**

1 2 3 4 5 88/Refused
99/Unknown

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

a. **Accomplished less than you would like.**
vr12dis4a

1 2 3 4 5 88/Refused
99/Unknown

b. Didn't do work or other activities as **carefully** as usual. **vr12dis4b**

1 2 3 4 5 88/Refused
99/Unknown

5. During the past 7 days, or since your burn if you were injured less than 7 days ago, how much did **pain** interfere with your normal work (including both work outside the home and house work)? **vr12dis5**

88/Refused
99/Unknown
14

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

BMS Adult Codebook Form I
NewMSID _____

NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1	2	3	4	5

These questions are about how you feel and how things have been with you past 7 days, or since your burn if you were injured less than 7 days ago. For each question, please give the one answer that comes closest to the way you have been feeling.

6. How much of the time past 7 days, or since your burn if you were injured less than 7 days ago:

	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? vr12dis6a	1	2	3	4	5	6	88/Refused 99/Unknown
b. Did you have a lot of energy? vr12dis6b	1	2	3	4	5	6	88/Refused 99/Unknown
c. Have you felt downhearted and blue? vr12dis6c	1	2	3	4	5	6	88/Refused 99/Unknown

7. In the past 7 days, or since your burn if you were injured less than 7 days ago, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)? **vr12dis7**

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

CAGE Alcohol use:

For these questions, data collectors ask the first four items and then sum the total and fill in the history of drug and history of alcohol use items below.

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. You don't need the response key for this section.

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.*

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 (**Eye-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 marijuana, 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 participants 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 **C**ut down on your drug use? Yes (1) No (0)

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

3. Have you ever felt **G**uilty 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)

These items are not asked aloud by data collectors.

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

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 CAGE Alcohol Use on page 17*)
- 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
- 88. Declined to answer/Refused
- 99. Unknown

77. Not applicable (no itching)

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

- | | |
|--|---|
| 1. <input type="checkbox"/> Not present | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Mild | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Moderate | |
| 4. <input type="checkbox"/> Severe | |
| 5. <input type="checkbox"/> Unbearable | |
| 77. <input type="checkbox"/> Not applicable (no itching) | |

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

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

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

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

DEMOGRAPHICS

This is the last section of the survey.

Interviewer Instructions: Use medical record for #1 and #2. 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. If disposition (#2, below) is not clear on Medical Record, clarify with participant.

1. What were the circumstances of your burn injury? (Choose only one) **circinj**

Interviewer Instructions: If necessary, ask this as open-ended, using, "Can you tell me about the circumstances of your burn injury?" If needed, in order to probe for location, ask "Did it happen work, at home, or somewhere else?" If someone else caused it, in order to probe for intentionality, ask "Was it intentional?" If the person him/herself caused it, be cautious about probing for intentionality, and, if okay, ask "Did you mean to?"

1. Non-intentional employment related
2. Non-intentional non-work related (*Interviewer Instructions: choose this category if employment and/or recreation do not apply*)
3. Non-intentional recreation
4. Non-intentional non-specified (*Interviewer Instructions: 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
- 88. Declined to answer/Refused
- 99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

2. Where will you go after you are discharged from the hospital for your burn? (Choose only one) **disposn**

- 1. Died, burn related
- 2. AMA/Unable to complete treatment
- 3. Patient home
- 4. Other home (includes hospital owned apartments)
- 6. Extended care facility
- 8. Other rehab facility (not model system)
- 9. Institution
- 10. Drug/alcohol treatment center
- 11. Shelter
- 12. Street
- 13. Died, non-burn related
- 14. Other
- 88. Declined to answer/Refused
- 99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

1. What is your race and/or ethnicity? (Choose only one) **ethncity**

- 1. White, non-Hispanic (including Middle Eastern and Indian)
- 2. Black, non-Hispanic
- 3. Hispanic
- 4. Pacific Islander
- 5. Asian
- 6. Native American
- 7. Multi-Racial
- 8. Other
- 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. After your discharge, where will you be living? (Choose only one) **dislvisit**

- 1. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 88. Declined to answer/Refused
- 99. Unknown

- 5. Homeless
- 6. Other

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

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

- 1. Alone livhisdis__1
- 2. Spouse/partner/significant other livhisdis __2
- 3. Friend livhisdis __3
- 4. Parent or step-parent livhisdis __4
- 5. Other relative (siblings, grandparents) livhisdis __5
- 6. Others, not part of family livinga__6
- 7. Guardian livhisdis __7
- 8. Young children livhisdis __8
- 9. Adult children livhisdis __9
- 88. Declined to answer/Refused livhisdis __88
- 99. Unknown livhisdis__99

The previous variable “livhsdis” was changed with the move to the new forms in 2015 to include options for choose all that apply. Clarification was also added to “other relative” option to include “siblings, grandparents”, “other”, to include “not part of family”.

4. 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?”*) 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
- 88. Declined to answer/Refused
- 99. Unknown

- 11. 11 or 12 years; no diploma
- 12. High school diploma
- 13. Work towards Associate's degree
- 14. Associate's degree
- 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

Interviewer Instructions: Skip to #6, on the next page, if participant has a high school diploma or higher.

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

- 1. No
- 2. Yes
- 77. Not applicable (high school diploma or higher)
- 88. Declined to answer/Refused
- 99. Unknown

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

- 1. I am 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 **disincdiso**_____
- 88. Declined to answer/Refused
- 99. Unknown

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

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

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

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

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

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

BMS Adult Codebook Form I
NewMSID_____

- 1. No
- 2. Yes
- 88. Decline 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: _____

Please answer each question as it relates to your current health:	
1. Hearing loss? hlossdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
2. Change in voice? voicedis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
3. Vision problems not corrected by glasses or contact lenses? visiondis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
4. Eyelid problems? eyeliddis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
5. Excessive tearing of the eyes? teardis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
6. Difficulty with memory? memorydis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
7. Difficulty with thought processing? thoughtdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
8. Numbness, pins and needles or burning sensations in your burn scar? numbscdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
9. Numbness, pins and needles or burning sensations in your hands? numbhdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
10. Numbness, pins and needles or burning sensations in your feet? numbfdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
11. Trouble with your balance? tbalandis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
12. Varicose veins? varveindis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99

13. Swollen feet or legs? swflegdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
14. Swollen hands or arms? swharmdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
15. Difficulty breathing when doing your regular daily activities? difbrergdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
16. Difficulty breathing when exercising? difbreexdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
17. Skin cancer? skincandis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
18. Joint pain? jpaindis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
19. Have you had any urinary tract infections (bladder infections or UTIs) in the past year? About how many? numutidis	<input type="checkbox"/> None=0 <input type="checkbox"/> One=1 <input type="checkbox"/> More than 1=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
20. Blood clots in legs or lungs? bclelungdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
21. Cold intolerance? cintoldis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
22. Excessive sweating? exsweatdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
23. Difficulty in hot environments? difhotdis	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99

FT2. 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. 1 year follow-up
 3. 2 year 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 **Option 14 added with new forms in 2015**

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

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.

Answer Key:

If the participant was sent or was given an answer key, say, "Do you have your answer key in front of you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. If the participant was not sent an answer key, go to the second bullet below.

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- *If the answer is no and this is a telephone interview, or if the participant was not sent an answer key, say, "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- *If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

Let's get started.

Burn Injury Follow-up

1. Do you drive a car? **drive**

- 1. Yes (*Interviewer Instructions: Skip #2 and continue with #3, below*)
- 2. No
- 88. Declined to answer/Refused
- 99. Unknown

Added in 2015

2. If not, is the reason burn related? **bdrive**

- 1. Yes
- 2. No
- 77. Not applicable (participant does drive)
- 88. Declined to answer/Refused
- 99. Unknown

Added in 2015

Interviewer Instructions: If the person is not driving, skip to #4. If the participant does drive, continue below.

3. Do you use adaptive equipment to drive? **adaptdrive**

- 1. Yes
- 2. No
- 77. Not applicable (participant does not drive)
- 88. Declined to answer/Refused
- 99. Unknown

Added in 2015

4. Since your last interview, have you received psychological therapy or counseling due to your burn injury? **pyschther**

- 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.

5. 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

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

- 1. No services (*Interviewer Instructions: skip to #10, surgery item, on page 6*)
- 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**

services__1

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 #10, surgery item, on page 6.

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

7. How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? _____ (fill in # of sessions) (Code 77 for N/A—no services received, 88 for declined to answer/refused, and code 99 for unknown number of sessions)

numserv

Added in 2015

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

8. Burn center?

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

9. 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

10. Since your last interview [provide date], have you had any burn related surgeries? surgery_fu

1. Yes

2. No (*Interviewer Instructions: skip to Demographics on page 8*)

99. Don't know (*Interviewer Instructions: skip to Demographics on page 8*)

88. Declined to answer/Refused

New coding for 88/99 added in 2015

Interviewer Instructions: Continue with these questions if the participant had burn related surgeries

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

1. Yes

2. No (*Interviewer Instructions: skip to Demographics on page 8*)

99. Don't know (*Interviewer Instructions: skip to Demographics on page 8*)

88. Declined to answer/Refused

Added in 2015

Interviewer Instructions: If the participant had surgeries only at the BMS center (ie, they said yes to #10 above and no to #11 above), fill in number 12 and 13 below, about number of surgeries and types of surgeries (and the amputation section, if applicable), using the Medical Record and then move on to Demographics on page 8. If yes to #11 (participant had burn related surgeries outside the BMS center), continue with questions #12 and #13, and indicate that the data was obtained using self-report.

Interviewer Instructions: Continue with these questions if the participant had burn related surgeries outside the BMS center. To help them clarify, say, "We'd like to know how any procedures you had that involved anesthesia, but were for something other than a dressing or cast change. Can you remember?"

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.

12. How many surgeries did you have, including those outside of [name the BMS center]?

_____ (code 77 for N/A—no surgery and code 99 for unknown number of surgeries)

num surg (added in 2015)

Source of number of surgeries: Self-report -1 Medical record-2

src_numsurg (77—Not applicable (no surgeries))

13. Which burn related surgeries have you had since your last interview?

(Choose all that apply)

- 1. Surgery for open wounds **surgtype__1** **surgtype__88**
- 2. Surgery for joint contractures **surgtype__2** **99. Unknown **surgtype__99****
- 3. Surgery for scar management **surgtype__3**
- 4. Amputation **surgtype__4** (*Interviewer Instructions: if the participant indicates he/she has had surgery for amputation go on to the Amputation section below. If not, skip to Demographics on page 8*)
- 5. Other **surgtype__5** (if so, what? _____ **otrsurg** _____)
- 77. Not applicable (no surgery) **surgtype__77**

0=not checked

1=checked

Added in 2015

Source of type of surgeries: Self-report -1 Medical record-2

src_surgtype (77—Not applicable (no surgeries))

Amputations

Interviewer Instructions: if the participant hasn't had surgery for amputation, skip to Demographics on page 8. Fill out this information using the medical record unless the amputation was performed outside the BMS center.

1. Have you had an upper extremity amputation due to burn injury since your last interview?

(Choose all that apply) *Interviewer Instructions: ask as open ended and then mark the correct response.*

- 1. No **amputfu1__1**; 0=not checked; 1=checked
- 2. Yes, above elbow right **amputfu1__2**; 0=not checked; 1=checked
- 3. Yes, above elbow left **amputfu1__3**; 0=not checked; 1=checked
- 4. Yes, above elbow bilateral **amputfu1__4**; 0=not checked; 1=checked
- 5. Yes, below elbow right **amputfu1__5**; 0=not checked; 1=checked
- 6. Yes, below elbow left **amputfu1__6**; 0=not checked; 1=checked
- 7. Yes, below elbow bilateral **amput1__7**; 0=not checked; 1=checked
- 8. Yes, digits only right **numudgtrfu**____(fill in # of digits) (Thumb amputated? **thumbrfu**
1-Yes 2-No, **99-Unknown**) **amputfu1__8**; 0=not checked; 1=checked
- 9. Yes, digits only left **numudgtlfu**____(fill in # of digits) (Thumb amputated?
thumblfu 1-Yes 2-No, **99-Unknown**) **amputfu1__9**; 0=not checked; 1=checked
- 10. Yes, digits only bilateral **numudgtbfu**____(fill in # of digits) (Thumbs amputated?
thumbbfu 1-Yes 2-No, **99-Unknown**) **amputfu1__10**; 0=not checked; 1=checked

Notes:

New variable added with new Forms in 2015

88. Declined to answer/Refused--
amputfu1__88

99. Unknown **amputfu1__99**

2. Have you had a lower extremity amputation due to burn injury since your last interview?
 (Choose all that apply) *Interviewer instructions: ask as open ended and then mark the correct response.*

1. No amputfu2__1; 0=not checked; 1=checked
2. Yes, above knee right amputfu2__2; 0=not checked; 1=checked
3. Yes, above knee left amputfu2__3; 0=not checked; 1=checked
4. Yes, above knee bilateral amputfu2__4; 0=not checked; 1=checked
5. Yes, below knee right amputfu2__5; 0=not checked; 1=checked
6. Yes, below knee left amputfu2__6; 0=not checked; 1=checked
7. Yes, below knee bilateral amputfu2__7; 0=not checked; 1=checked
8. Yes, digits only right numldgrfu _____(fill in # of digits) amputfu2__8; 0=not checked; 1=checked
9. Yes, digits only left numldglfu _____(fill in # of digits) amputfu2__9; 0=not checked; 1=checked
10. Yes, digits only bilateral numldgtbfu _____(fill in # of digits) amputfu2__10; 0=not checked; 1=checked
11. Transmetatarsal right (partial foot amputation right) amputfu2__11; 0=not checked; 1=checked
12. Transmetatarsal left (partial foot amputation left) amputfu2__12; 0=not checked; 1=checked
13. Transmetatarsal bilateral (partial foot amputation bilateral) amputfu2__13; 0=not checked; 1=checked

88. Declined to answer/Refused amputfu2__88
 99. Unknown amputfu2__99

Notes:

New variable added with new Forms in 2015

Source of amputation data: Self-report Medical record

Health Status

1. Have you had another major injury requiring hospitalization since your last interview?

majhosp

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

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 (Pain Medication on page 5) if the participant has already filled out the Review of Systems for this data collection time-point.*)

Refer to Review of Systems Followup Data Dictionary for variable names.

Please answer each question as it relates to your current health:				
1. Hearing loss?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
2. Change in 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?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
4. Eyelid problems?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
5. Excessive tearing of the eyes?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
6. Difficulty with memory?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused
7. Difficulty with thought processing?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know	88/Refused

2. No (*Interviewer instructions: skip to the VR12 section on page 16*)

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 =0	Never affects sleep=1	Occasional ly delays falling asleep=2	Frequently delays falling asleep=3	Delays falling asleep and occasionally wakes me up at night=4	Delays falling asleep and frequently wakes me up at night=5
Sleep itch4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88 / 99

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

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	88/Refused 99/Unknown
1	2	3	4	5	

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?

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? **vr12_2a**

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?

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** **vr12_3a.**

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)?

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.** **vr12_4a**

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	88/Refused 99/Unknown
b. Didn't do work or other activities as carefully as usual. vr12_4b	1	2	3	4	5	

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	88/Refused 99/Unknown
1	2	3	4	5	

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.

Look at your Answer Key on page 2, Section 3, Option E

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	88/Refused 99/Unknown
a. Have you felt calm and peaceful? vr12_6a	1	2	3	4	5	6	
b. Did you have a lot of energy? vr12_6b	1	2	3	4	5	6	
c. Have you felt downhearted and blue? vr12_6c	1	2	3	4	5	6	

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	88/Refused 99/Unknown
1	2	3	4	5	

Interviewer Instructions: If this is a 2 year, 5 year, 10 year, etc interview, continue below. If it is a 6 month or 12 month interview, skip #8 and #9 and move on to PHQ-9 #9 on page 9.

Now, we'd like to ask you some questions about how your health may have changed.

8. Compared to one year ago, how would you rate your **physical health** in general now? **vr12_8**

MUCH BETTER SLIGHTLY BETTER ABOUT THE SAME SLIGHTLY WORSE MUCH WORSE

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

1	2	3	4	5	88/Refused 99/Unknown
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N/A: 6 or 12 month interview

9. Compared to one year ago, how would you rate your emotional problems (such as feeling anxious, depressed or irritable) now?
vr12_9

MUCH BETTER	SLIGHTLY BETTER	ABOUT THE SAME	SLIGHTLY WORSE	MUCH WORSE	88/Refused 99/Unknown
1	2	3	4	5	

N/A: 6 or 12 month interview

PHQ-9 #9

Interviewer instructions: Be informed of your center’s protocol for suicidal ideation, and follow those procedures if the participant chooses #3 or #4 (endorses suicidal ideation) with this item. If desired, indicate to the participant that this item is sensitive by saying, “The next question may be hard to answer or talk about.”

1. In the past two weeks, how often were you bothered by thoughts that you would be better off dead or of hurting yourself in some way? phq9_9_fup

1. Not at all =0

2. Several days =1

3. More than half the days =2

4. Nearly every day =3

88. Declined to answer/Refused

99. Unknown

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

BMS Adult Codebook Form II

	=5	=4	=3	=2		
1. Are you able to do chores such as vacuuming or yard work? pfa11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
2. Are you able to go up and down stairs at a normal pace? pfa21	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
4. Are you able to run errands and shop? pfa53	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown

ANXIETY

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

DEPRESSION

In the past 7 days...	Never=1	Rarely=2	Some-times=3	Often=4	Always=5	
9. I felt worthless eddep04	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
10. I felt helpless eddep06	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
11. I felt depressed eddep29	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
12. I felt hopeless eddep41	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown

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FATIGUE

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

SLEEP DISTURBANCE

In the past 7 days...	Very poor=5	Poor=4	Fair=3	Good=2	Very good=1	
17. My sleep quality was sleep109	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
In the past 7 days...						
	Not at all	A little bit	Somewhat	Quite a bit	Very much	
18. 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
19. 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
20. 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

ABILITY TO PARTICIPATE IN SOCIAL ROLES AND ACTIVITIES

	Never=5	Rarely=4	Sometimes=3	Usually=2	Always=1	
21. I have trouble doing all of my regular leisure activities with others srpper11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
22. I have trouble doing all of the family activities that I want to do srpper18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
23. I have trouble doing all of my usual work (include work at home) srpper23	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown

24. I have trouble doing all of the activities with friends that I want to do srpper46	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
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PAIN INTERFERENCE

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

Pain Intensity

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

NeuroQOL Stigma Short Form:

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	Some-times=3	Often=4	Always =5	
1. Because of my injury, some people avoided me. nqstg02	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown

2. Because of my injury, I felt left out of things. nqstg04	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
3. Because of my injury, people avoided looking at me. nqstg08	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
4. I felt embarrassed about my injury. nqstg16	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
5. Because of my injury, some people seemed uncomfortable with me. nqstg01	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
6. I felt embarrassed because of my physical limitations. nqstg17	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown
7. Because of my injury, people were unkind to me. nqstg05	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused 99/Unknown

Burn Specific Health 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.

How much difficulty do you have:	Extreme(ly) =0	Quite a bit =1	Moderate(ly) =2	A little bit =3	None (not at all) =4	
BH1. Bathing independently? bshs_1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH2. Dressing yourself? bshs_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH3. Getting in and out of a chair? bshs_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH4. Signing your name? bshs_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH5. Eating with utensils? bshs_5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH6. Tying shoelaces, bows, etc? bshs_6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH7. Picking up coins from a flat surface? bshs_7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH8. Turning a doorknob? bshs_8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH9. Working in your old job performing your old duties? bshs_9	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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	

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

BMS Adult Codebook Form II

BH10. I am troubled by feelings of loneliness. <i>bshs_10</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH11. I often feel sad or blue. <i>bshs_11</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH12. At times, I think I have an emotional problem. <i>bshs_12</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH13. I am not interested in doing things with my friends. <i>bshs_13</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH14. I do not enjoy visiting people. <i>bshs_14</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH15. I have no one to talk to about my problems. <i>bshs_15</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH16. I have feelings of being trapped or caught. <i>bshs_16</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH17. My injury has put me further away from my family. <i>bshs_17</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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	
BH18. I would rather be alone than with my family. <i>bshs_18</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH19. I do not like the way my family acts around me. <i>bshs_19</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH20. My family would be better off without me. <i>bshs_20</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH21. I feel frustrated because I cannot be sexually aroused as well as I used to. <i>bshs_21</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH22. I am simply not interested in sex anymore. <i>bshs_22</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH23. I no longer hug, hold, or kiss. <i>bshs_23</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH24. Sometimes, I would like to forget that my appearance has changed. <i>bshs_24</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH25. I feel that my burn is unattractive to others. <i>bshs_25</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH26. My general appearance really bothers me. <i>bshs_26</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH27. The appearance of my scars bothers me. <i>bshs_27</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH28. Being out in the sun bothers me. <i>bshs_28</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH29. Hot weather bothers me. <i>bshs_29</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH30. I cannot get out and do things in hot weather. <i>bshs_30</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

BH31. It bothers me that I cannot get out in the sun. bshs_31	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH32. My skin is more sensitive than before. bshs_32	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH33. Taking care of my skin is a bother. bshs_33	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH34. There are things I have been told to do for my burn that I dislike doing. bshs_34	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH35. I wish I did not have to do so many things to take care of my burn. bshs_35	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH36. I have a hard time doing all the things I have been told to take care of my burn. bshs_36	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH37. Taking care of my burn makes it hard to do other things that are important to me. bshs_37	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH38. My burn interferes with my work. bshs_38	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH39. Being burned has affected my ability to work. bshs_39	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
BH40. My burn has caused problems with my working. bshs_40	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

CAGE Alcohol Use:

Now I have a few questions about alcohol and drugs.

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

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 marijuana, 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 participants states they do not drink after the first question, you can fill in “No” for all four questions and skip to Pain Medication on page 15.

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Repeated, disturbing <i>dreams</i> of your burn injury? pclc_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Suddenly <i>acting or feeling</i> as if your burn injury were <i>happening</i> again (as if you were reliving it)? pclc_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. Avoid <i>activities or situations</i> because they <i>remind you</i> of your burn injury? pclc_7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

8. Trouble remembering important parts of your burn injury? pclc_8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. Loss of interest in things that you used to enjoy? pclc_9	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. Feeling distant or cut off from other people? pclc_10	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. Feeling emotionally numb or being unable to have loving feelings for those close to you? pclc_11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Feeling as if your future will somehow be cut short? pclc_12	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
13. Trouble falling or staying asleep? pclc_13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
14. Feeling irritable or having angry outbursts? pclc_14	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
15. Having difficulty concentrating? pclc_15	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
16. Being "super alert" or watchful on guard? pclc_16	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
17. Feeling jumpy or easily startled? pclc_17	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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
- 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

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: s11	<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: s12	<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 s13	<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 s14	<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: s15	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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	1	2	3	4	5	
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

DEMOGRAPHICS:

Finally I have some general questions about you.

Interviewer instructions: Record participant's height and weight in pounds and feet/inches

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

Added to adult data collection in 2015

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

Added to adult data collection in 2015

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

- | | |
|---|---|
| 1. <input type="checkbox"/> House | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Apartment | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Mobile home | |
| 4. <input type="checkbox"/> Institution | |
| 5. <input type="checkbox"/> Homeless | |
| 6. <input type="checkbox"/> Other | |

4. What is your current zip code? _____ **zipfu**
(Code 99999 for unknown, code 00000 for Mexico)

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

For all variables, 0=not checked; 1=checked

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

- | | |
|--|---|
| 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) | |
| 99. <input type="checkbox"/> Unknown | |

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

"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."

hincatfu

- | | |
|---|---|
| 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. \$200,000 or more
- 7. Living outside the United States
- 77. Not applicable (e.g., living in an institution)

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)

8. In the past year, how many months did you work at a regular job? ___**mrjobfup**____months) (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

9. 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?) **occfup**

Occupation: _____
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

10. What is your current employment status? **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
- 88. Declined to answer/Refused
- 99. Unknown

→ *Instructions: skip to #10, below*

66-"Not working" on old forms
77-Not applicable due to age

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".

Interviewer instructions: Skip #11 and move on to #12 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.

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

Entered into the patient status form: returndat

12. 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#13and move on to #14 on this 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).

13. Approximately what was your individual income for the past full year?

iinccatfup

1. Less than \$25,000

2. \$25,000-\$40,999

3. \$41,000-\$55,999

4. \$56,000-\$70,999

5. \$71,000-\$85,999

6. \$86,000-\$100,000

7. Greater than \$100,000

8. Living outside the United States

77. Not applicable (no individual income)

88. Declined to answer/Refused

99. Unknown

14. What is your current school status? aschoolfu

1. In School (*Interviewer Instructions: Continue with #15 on the next page if this is a 6, 12, or 24 month follow-up. Skip to #17 on page 12 if this is a 5, 10, or 15 year follow-up.*)

2. Not in School (*Interviewer Instructions: Skip to #16 on page 11*)

99. Unknown

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

15. ...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). **aprogfu**

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

- | | |
|---|---|
| 1. <input type="checkbox"/> Same program full time | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Same program part time | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> New program full time | |
| 4. <input type="checkbox"/> New program part time | |
| 5. <input type="checkbox"/> Did not resume school | |
| 6. <input type="checkbox"/> Returned to individual program, home school | |
| 7. <input type="checkbox"/> Not in school | |
| 77. Not applicable—5, 10, 15, etc, year follow-up. | |

Interviewer Instructions: Skip to #17 on the next page if the participant is going to work or school.

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

- | | |
|--|---|
| 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 |
| 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 | |
| 10. <input type="checkbox"/> Homemaker/caregiver | |
| 11. <input type="checkbox"/> Unemployed but actively seeking employment | |
| 77. <input type="checkbox"/> Not applicable (working or going to school) | |

17. 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?"*).

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

educfup

- | | |
|--|---|
| 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. 10 years
- 11. 11 or 12 years; no diploma
- 12. High school diploma
- 13. Work towards Associate's degree
- 14. Associate's degree
- 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

Interviewer Instructions: Skip to #19 below if the participant has a high school diploma or attended college or if they have already answered "yes" to the GED item in a previous interview.

18. Did you earn a GED instead of graduating from high school? **gedfup**
- 1. No
 - 2. Yes
 - 77. Not applicable (high school diploma or attended college)
 - 88. Declined to answer/Refused
 - 99. Unknown

19. 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 #21 on page 13, 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 #20

20. 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

21. 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

22. Do you currently have any psychological issues, such as depression or anxiety? **pyschisfup**

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

23. 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. <input type="checkbox"/> Medicare | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Medicaid (DSHS) | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Private insurance | |
| 4. <input type="checkbox"/> Worker's compensation (L&I) | |
| 5. <input type="checkbox"/> HMO/PPO/Pre-paid/Managed Care | |
| 6. <input type="checkbox"/> Champus/Tri-Care | |
| 7. <input type="checkbox"/> Self-pay | |
| 8. <input type="checkbox"/> Indigent (public support; charity care) | |
| 9. <input type="checkbox"/> VA | |
| 10. <input type="checkbox"/> Other | |
| 11. <input type="checkbox"/> Philanthropy (private support) | |
| 77. <input type="checkbox"/> Not applicable (no burn care costs) | |

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

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

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

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

Please answer each question as it relates to your <u>current</u> health:	
1. Hearing loss? hloss	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
2. Change in voice? voice	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
3. Vision problems not corrected by glasses or contact lenses? vision	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
4. Eyelid problems? eyelid	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
5. Excessive tearing of the eyes? tear	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
6. Difficulty with memory? memory	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
7. Difficulty with thought processing? thought	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
8. Numbness, pins and needles or burning sensations in your burn scar? numbsc	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
9. Numbness, pins and needles or burning sensations in your hands? numbh	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
10. Numbness, pins and needles or burning sensations in your feet? numbf	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
11. Trouble with your balance? tbalan	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
12. Varicose veins? varvein	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99

13. Swollen feet or legs? swfleg	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
14. Swollen hands or arms? swharm	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
15. Difficulty breathing when doing your regular daily activities? difbrerg	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
16. Difficulty breathing when exercising? difbreex	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
17. Skin cancer? skincanc	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
18. Joint pain? jpain	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
19. Have you been pregnant or fathered a child since your last interview? preg_fath	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
20. Blood clots in legs or lungs? bclelung	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
21. Cold intolerance? cintol	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
22. Excessive sweating? exsweat	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99
23. Difficulty in hot environments? difhot	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=2 <input type="checkbox"/> Skipped/Refused=88 <input type="checkbox"/> Don't know/Missing=99

Date Medication Data Collected: ____ ____ / ____ ____ / ____ ____

Medication must be prescribed during the follow-up data collection window.

1. Follow-up period

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

Name of Medication (prescribed in data collection window)	
1.	med1
2.	med2
3.	med3
4.	med4
5.	med5
6.	med6
7.	med7
8.	med8
9.	med9
10.	med10

NewMSID _____

11. med11
12. med12

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 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; 0=not checked; 1=checked**
 2. Medical Record Abstraction Form **status__2; 0=not checked; 1=checked**
 3. Review of Systems Checklist Form **status__3; 0=not checked; 1=checked**
 4. 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.

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.

Answer Key:

If the interview is over the phone and the participant was sent an answer key, say, "Did you receive your answer key that we sent you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. *If the participant was not sent an answer key, go to the second bullet below.*

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- *If the answer is no, or if the participant was not sent an answer key, say "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- *If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

If the interview is in person and the participant has an answer key, say, "The answer key I gave you shows the responses you can choose from when you answer the questions I'll be asking. I will tell you when to use the answer key.

Let's get started. The first section is about your current health.

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 | 2 | 3 | 4 | 5 | 6 | 7 |
| <i>Not at all</i> | <i>To a very small extent</i> | <i>To a small extent</i> | <i>To a moderate extent</i> | <i>To a fairly great extent</i> | <i>To a great extent</i> | <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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Hearing? chcself2, chcself2a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Learning and understanding? chcself3, chcself1a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. Controlling emotions or behavior? chcself5, chcself5a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. with Seizures or epilepsy? chcself6, chcself6a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. with Teeth and gums? chcself8, chcself8a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. with Type 1 or Type 2 diabetes? chcself10, chcself10a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. with Growth? chcself11, chcself11a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Sleeping? chcself12, chcself12a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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? <i>chcself18, chcself18a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
---	---	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	---------

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

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.

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

These questions added with new forms in December 2015.

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. <i>pa066pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My life was just right <i>pa067pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I had a good life <i>pa070pre</i>	<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 <i>pa071pre</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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? **ci2_pre**

- | | |
|---------------------------------------|---|
| 1. <input type="checkbox"/> Often | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Sometimes | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> 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. <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. **ci4_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 **ci5_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?

- | | |
|---|---|
| ci6_pre | 88. <input type="checkbox"/> 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 | |

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

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

Pre-Injury Demographics

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

- | | |
|---|---|
| 1. <input type="checkbox"/> House | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Apartment | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Mobile home | |
| 4. <input type="checkbox"/> Institution | |
| 5. <input type="checkbox"/> Homeless | |
| 6. <input type="checkbox"/> Other | |

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?"

2. What was your zip code at the time of your burn injury? ___ ___ ___ ___ ___ **zip_pre**

(Code 99999 for unknown, code 00000 for Mexico)

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** 88. Declined to answer/Refused
 5. Other relative (siblings, grandparents) **livinga__5** 99. Unknown
 6. Others, not part of family **livinga__6**
 7. Guardian **livinga__7**

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.

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

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

6. 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 88. Declined to answer/Refused
 2. No 99. Unknown

7. Before the burn, did you have any psychological issues, such as depression or anxiety?

psychis

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

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

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

Demographics

This is the last section of the survey.

Interviewer Instructions: Use medical record for #1 and #2. 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. If disposition (#2, below) is not clear on Medical Record, clarify with participant.

1. What were the circumstances of your burn injury? (Choose only one) **circinj**

Interviewer Instructions: If necessary, ask this as open-ended, using, “Can you tell me about the circumstances of your burn injury?” If needed, in order to probe for location, ask “Did it happen work, at home, or somewhere else?” If someone else caused it, in order to probe for intentionality, ask “Was it intentional?” If the person him/herself caused it, be cautious about probing for intentionality, and, if okay, ask “Did you mean to?”

1. Non-intentional employment related
2. Non-intentional non-work related (*Interviewer Instructions: choose this category if employment and/or recreation do not apply*)
3. Non-intentional recreation
4. Non-intentional non-specified (*Interviewer Instructions: 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
88. Declined to answer/Refused
99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

2. Where will you go after you are discharged from the hospital for your burn? (Choose only one) **disposn**

1. Died, burn related
2. AMA/Unable to complete treatment
3. Patient home
4. Other home (includes hospital owned apartments)
6. Extended care facility
8. Other rehab facility (not model system)
9. Institution
10. Drug/alcohol treatment center
11. Shelter
12. Street
13. Died, non-burn related
14. Other
88. Declined to answer/Refused
99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

1. What is your race and/or ethnicity? (Choose only one) **ethncity**

- | | | | |
|-----------------------------|---|------------------------------|----------------------------|
| 1. <input type="checkbox"/> | White, non-Hispanic (including Middle Eastern and Indian) | 88. <input type="checkbox"/> | Declined to answer/Refused |
| 2. <input type="checkbox"/> | Black, non-Hispanic | 99. <input type="checkbox"/> | Unknown |
| 3. <input type="checkbox"/> | Hispanic | | |
| 4. <input type="checkbox"/> | Pacific Islander | | |
| 5. <input type="checkbox"/> | Asian | | |
| 6. <input type="checkbox"/> | Native American | | |
| 7. <input type="checkbox"/> | Multi-Racial | | |
| 8. <input type="checkbox"/> | Other | | |

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

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

- | | | | |
|-----------------------------|-------------|------------------------------|----------------------------|
| 1. <input type="checkbox"/> | House | 88. <input type="checkbox"/> | Declined to answer/Refused |
| 2. <input type="checkbox"/> | Apartment | 99. <input type="checkbox"/> | Unknown |
| 3. <input type="checkbox"/> | Mobile home | | |
| 4. <input type="checkbox"/> | Institution | | |
| 5. <input type="checkbox"/> | Homeless | | |
| 6. <input type="checkbox"/> | Other | | |

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

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

- | | | | |
|-----------------------------|---|------------------------------|---|
| 4. <input type="checkbox"/> | Parent or step-parent livhisdis ___4 | | |
| 5. <input type="checkbox"/> | Other relative (siblings, grandparents) livhisdis ___5 | | |
| 6. <input type="checkbox"/> | Others, not part of family livinga___6 | 88. <input type="checkbox"/> | Declined to answer/Refused livhisdis ___88 |
| 7. <input type="checkbox"/> | Guardian livhisdis ___7 | 99. <input type="checkbox"/> | Unknown livhisdis___99 |

The previous variable “livhsdis” was changed with the move to the new forms in 2015 to include options for choose all that apply. Clarification was also added to “other relative” option to include “siblings, grandparents”, “other”, to include “not part of family”.

4. 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. <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. 9 years
- 10. 10 years
- 11. 11 or 12 years; no diploma
- 12. High school diploma
- 66. Other

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

- 1. I am 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 **disin****diso**_____

- 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: _____

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 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; 0=not checked; 1=checked
2. Medical Record Abstraction Form status__2; 0=not checked; 1=checked
3. Review of Systems Checklist Form status__3; 0=not checked; 1=checked
4. 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.

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.

Answer Key:

If the interview is over the phone and the participant was sent an answer key, say, "Did you receive your answer key that we sent you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. *If the participant was not sent an answer key, go to the second bullet below.*

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- *If the answer is no, or if the participant was not sent an answer key, say "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- *If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

If the interview is in person and the participant has an answer key, say, "The answer key I gave you shows the responses you can choose from when you answer the questions I'll be asking. I will tell you when to use the answer key.

Let's get started. The first section is about your child's current health.

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 | 2 | 3 | 4 | 5 | 6 | 7 |
| <i>Not at all</i> | <i>To a very
small extent</i> | <i>To a small
extent</i> | <i>To a moderate
extent</i> | <i>To a fairly
great extent</i> | <i>To a great
extent</i> | <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? <i>chcprox1, chcprox1a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Hearing? <i>chcprox2, chcprox2a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Learning and understanding? <i>chcprox3, chcprox3a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? <i>chcprox4, chcprox4a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. Controlling emotions or behavior? <i>chcprox5, chcprox5a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. with Seizures or epilepsy? <i>chcprox6, chcprox6a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? <i>chcprox7, chcprox7a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. with Teeth and gums? <i>chcprox8, chcprox8a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? <i>chcprox9, chcprox9a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. with Type 1 or Type 2 diabetes? <i>chcprox10, chcprox10a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. with Growth? <i>chcprox11, chcprox11a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Sleeping? <i>chcprox12, chcprox12a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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? <i>chcprox13, chcprox13a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? <i>chcprox14, chcprox14a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? <i>chcprox15, chcprox15a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? <i>chcprox16, chcprox16a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? <i>chcprox17, chcprox17a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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? <i>chcprox18, chcprox18a</i>	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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

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.

1. In the month before your child's burn injury did he/she take prescription medication for pain on a regular basis? *pmedprx_pre* 88. Declined to answer/Refused
 1. Yes 99. Unknown
 2. No

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

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

These questions added with new forms in December 2015.

Pre-Injury Demographics

1. Before your child's burn injury, where was he/she living? (Choose only one) *resdencprx*
 1. House 88. Declined to answer/Refused
 2. Apartment 99. Unknown
 3. Mobile home
 4. Institution
 5. Homeless
 6. Other

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)

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*
 7. Guardian *livingaprx__7* *livingaprx__88*, 88. Declined to answer/Refused
livingaprx__99, 99. Unknown

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 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. 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 psychological issues, such as depression or anxiety? **psychisprx**

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

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

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

Demographics

Interviewer Instructions: Use medical record for #1 and #2. 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. If disposition (#2, below) is not clear on Medical Record, clarify with parent proxy

1. What were the circumstances of your child's burn injury? **circinj**

Interviewer instructions: Ask this as open-ended, using, “Can you tell me about the circumstances of your child's burn injury?” if necessary. If needed, in order to probe for location, ask “Did it happen at work, at home, or somewhere else?” If someone else caused it, in order to probe for intentionality, ask “Was it

intentional?" *If the child caused it, be cautious about probing for intentionality, and, if okay, ask "Did he/she mean to?"*

1. Non-intentional employment related (*Not applicable for pediatrics*)
2. Non-intentional non-recreation related (*Interviewer Instructions: choose this category if the burn involved an accident or fire at home that was non-recreational in nature*)
3. Non-intentional recreation
4. Non-intentional non-specified (*Interviewer Instructions: 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
88. Declined to answer/Refused
99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

2. Where will your child go after he/she is discharged from the hospital for his/her burn? (Choose only one) **disposn**

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 associated with this clinic/hospital)
9. Discharged, institution
10. Discharged, drug/alcohol treatment center
11. Discharged, shelter
12. Discharged, street
14. Other
88. Declined to answer/Refused
99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

1. What is your child's race and/or ethnicity? (Choose only one) **ethncity**

1. White, non-Hispanic (including Middle Eastern and Indian)
2. Black, non-Hispanic
3. Hispanic
4. Pacific Islander
5. Asian
6. Native American
7. Multi-Racial
8. Other
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. After your child’s hospital discharge, where will he/she be living? (Choose only one)

dislivsitprx

- 1. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 5. Homeless
- 6. Other
- 88. Declined to answer/Refused
- 99. Unknown

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

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

- 4. Parent or step-parent livhisdisprx__4
- 5. Other relative (siblings, grandparents) livhisdisprx__5
- 6. Others, not part of family livingprx__6
- 7. Guardian livhisdisprx__7

The previous variable “livhsdis” was changed with the move to the new forms in 2015 to include options for choose all that apply. Clarification was also added to “other relative” option to include “siblings, grandparents”, “other”, to include “not part of family”.

- 88. Declined to answer/Refused livhisdisprx__88
- 99. Unknown livhisdisprx__99

4. 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. Preschool completed
- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 77. Not applicable (child is too young for school)
- 88. Declined to answer/Refused
- 99. Unknown

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)?

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

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)

6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) **disin****disprx** 88. Declined to answer/Refused

1. My child is 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 _____ **disin****disopr**_____

7. Who is the primary sponsor of your child's care at hospital discharge? That is, who is paying for the majority of your child's burn care costs? (Choose only one) **sponsprx**

1. Medicare 88. Declined to answer/Refused
 2. Medicaid (DSHS) 99. Unknown
 3. Private insurance
 4. Worker's compensation (L&I)
 5. HMO/PPO/Pre-paid/Managed Care
 6. Champus/Tri-Care
 7. Self-pay
 8. Indigent (public support; charity care)
 9. VA
 10. Other
 11. Philanthropy (private support)

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, 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: _____

NIH Toolbox General Life Satisfaction

Indicate how much you agree or disagree:

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. papxy066pre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My child's life was just right.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>papxy067pre</i>					
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"/>

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: _____

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 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; 0=not checked; 1=checked
- 2. Medical Record Abstraction Form status__2; 0=not checked; 1=checked
- 3. Review of Systems Checklist Form status__3; 0=not checked; 1=checked
- 4. 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.*

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.

Answer Key:

If the interview is over the phone and the participant was sent an answer key, say, "Did you receive your answer key that we sent you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. *If the participant was not sent an answer key, go to the second bullet below.*

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- *If the answer is no, or if the participant was not sent an answer key, say "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- *If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

If the interview is in person and the participant has an answer key, say, "The answer key I gave you shows the responses you can choose from when you answer the questions I'll be asking. I will tell you when to use the answer key.

Let's get started. The first section is about your child's current health.

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 | 2 | 3 | 4 | 5 | 6 | 7 |
| Not at all | To a very
small extent | To a small
extent | To a moderate
extent | To a fairly
great extent | To a great
extent | 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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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? chcprox13, chcprox13a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox14, chcprox14a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox15, chcprox15a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox16, chcprox16a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)?	<input type="checkbox"/> Yes=1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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"/>	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. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 5. Homeless
- 6. Other
- 88. Declined to answer/Refused
- 99. Unknown

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)

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*
 - 7. Guardian *livingaprx__7*
 - 88. Declined to answer/Refused
 - 99. Unknown
- 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 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. 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 psychological issues, such as depression or anxiety? **psychisprx**

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

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

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

Demographics

Interviewer Instructions: Use medical record for #1 and #2. 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. If disposition (#2, below) is not clear on Medical Record, clarify with parent proxy

1. What were the circumstances of your child's burn injury? **circinj**

Interviewer instructions: Ask this as open-ended, using, "Can you tell me about the circumstances of your child's burn injury?" if necessary. If needed, in order to probe for location, ask "Did it happen at work, at home, or somewhere else?" If someone else caused it, in order to probe for intentionality, ask "Was it intentional?" If the child caused it, be cautious about probing for intentionality, and, if okay, ask "Did he/she mean to?"

- 1. Non-intentional employment related (Not applicable for pediatrics)
- 2. Non-intentional non-recreation related (*Interviewer Instructions: choose this category if the burn involved an accident or fire at home that was non-recreational in nature*)
- 3. Non-intentional recreation
- 4. Non-intentional non-specified (*Interviewer Instructions: 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
- 88. Declined to answer/Refused
- 99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

2. Where will your child go after he/she is discharged from the hospital for his/her burn? (Choose only one) **disposn**

- 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 associated with this clinic/hospital)
- 9. Discharged, institution
- 10. Discharged, drug/alcohol treatment center
- 11. Discharged, shelter
- 12. Discharged, street
- 14. Other
- 88. Declined to answer/Refused
- 99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

1. What is your child’s race and/or ethnicity? (Choose only one) **ethncity**

- 1. White, non-Hispanic (including Middle Eastern and Indian)
- 2. Black, non-Hispanic
- 3. Hispanic
- 4. Pacific Islander
- 5. Asian
- 6. Native American
- 7. Multi-Racial
- 8. Other
- 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. After your child’s hospital discharge, where will he/she be living? (Choose only one)

dislivsitprx

- 1. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 5. Homeless
- 6. Other
- 88. Declined to answer/Refused
- 99. Unknown

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

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

- 4. Parent or step-parent **livhisdisprx__4**
- 5. Other relative (siblings, grandparents) **livhisdisprx__5**
- 6. Others, not part of family **livingprx__6**
- 7. Guardian **livhisdisprx__7**

The previous variable “livhsdis” was changed with the move to the new forms in 2015 to include options for choose all that apply. Clarification was also added to “other relative” option to include “siblings, grandparents”, “other”, to include “not part of family”.

88. Declined to answer/Refused **livhisdisprx__88**

99. Unknown **livhisdisprx__99**

Interviewer instructions: Ask the question as open-ended

- 0. Preschool completed
- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 88. Declined to answer/Refused
- 99. Unknown

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)? _____ number field _____ hincnumpreprx
(Code 777 if not applicable; Code 888 if declined to answer/refused; Code 999 if missing/unknown)

Interviewer instructions: Fill in the number if the participant gives this information. Provide the following categories as options if the participant hesitates or can’t answer. If the person isn’t sure or doesn’t want to give a number, say “Let me read you some broad income categories. Please take your best guess if you don’t know the exact number. Here they are...”

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

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)

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

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

7. Who is the primary sponsor of your child’s care at hospital discharge? That is, who is paying for the majority of your child’s burn care costs? (Choose only one) sponsprx

- 1. Medicare
- 2. Medicaid (DSHS)
- 3. Private insurance
- 4. Worker’s compensation (L&I)
- 5. HMO/PPO/Pre-paid/Managed Care
- 6. Champus/Tri-Care
- 7. Self-pay
- 8. Indigent (public support; charity care)
- 9. VA
- 88. Declined to answer/Refused
- 99. Unknown

- 10. Other
- 11. Philanthropy (private support)

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: _____

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? **ci2prx_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**

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

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

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
- 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

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: _____

FT2. 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. 1 year follow-up
- 3. 2 year 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

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.

Answer Key:

If the participant was sent or was given an answer key, say, "Do you have your answer key in front of you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. If the participant was not sent an answer key, go to the second bullet below.

- If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.
- If the answer is no and this is a telephone interview, or if the participant was not sent an answer key, say, "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."
- If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."

Let's get started.

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I think people would not want to touch me. <i>bodyim_2</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I feel unsure of myself among strangers. <i>bodyim_3</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Changes in my appearance have interfered with my relationships. <i>bodyim_4</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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

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

BMS Pediatric 8-12 Codebook Form II

NewMSID_____

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	
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) <i>cpss_11</i>	<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) <i>cpss_12</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
13. Having trouble falling or staying asleep <i>cpss_13</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
14. Feeling irritable or having fits of anger <i>cpss_14</i>	<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) <i>cpss_15</i>	<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) <i>cpss_16</i>	<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) <i>cpss_17</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

PROMIS Anger

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

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. I felt mad <i>pr206r1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I felt upset <i>pr714r1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I felt fed up <i>pr5045r1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I was so angry I felt like throwing something <i>pr2319ar1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. I was so angry I felt like yelling at somebody <i>pr2581r1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. When I got mad, I stayed mad <i>proang_6</i> (not administered on spanish forms)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

PROMIS 25

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

Physical function mobility

In the past 7 days...	4=with no trouble	3=with a little trouble	2= With some trouble	1= With a lot of trouble	0=Not able to do	
1. I could do sports and exercise that other kids my age could do pr235r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I could get up from the floor pr4124r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I could walk up stairs without holding on to anything pr2707r2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I have been physically able to do the activities I enjoy most pr5023r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I felt nervous pr713r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I felt worried pr5044r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I worried when I was at home pr3459br1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I felt lonely pr711r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I felt sad pr228r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. It was hard for me to have fun pr3952ar2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

Fatigue

In the past 7 days...	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

BMS Pediatric 8-12 Codebook Form II
NewMSID _____

1. Being tired made it hard for me to keep up with my schoolwork pr4239ar2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I got tired easily pr2876r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I was too tired to do sports or exercise pr4241r2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I was too tired to enjoy the things I like to do pr4196r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I was able to count on my friends pr5058r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. My friends and I helped each other out pr5055r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Other kids wanted to be my friend pr233r2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. It was hard for me to pay attention when I had pain pr9004	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. It was hard for me to run when I had pain pr2045r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. It was hard for me to walk one block when I had pain pr2049r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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	Agree=4	Strongly Agree=5
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Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric 8-12 Codebook Form II
NewMSID _____

			Disagree=3			
1. My life is going well pa066	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My life is just right pa067	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I have a good life pa070	<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 pa071	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I felt angry when I was itching bmsitch_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I had trouble doing schoolwork when I was itching bmsitch_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. It was hard for me to pay attention when I was itching bmsitch_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. It was hard for me to have fun when I was itching bmsitch_5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
2. I can now handle big problems better than I used to. ptgic_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
3. I know what is important to me better than I used to. ptgic_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
4. I understand how God works better than I used to. ptgic_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
5. I feel closer to other people (friends or family) than I used to. ptgic_5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
6. I appreciate (enjoy) each day more than I used to. ptgic_6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused

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

BMS Pediatric 8-12 Codebook Form II

NewMSID_____

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

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: _____

FT2. 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. 1 year follow-up
- 3. 2 year 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

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.

Answer Key:

If the participant was sent or was given an answer key, say, "Do you have your answer key in front of you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. If the participant was not sent an answer key, go to the second bullet below.

- If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- If the answer is no and this is a telephone interview, or if the participant was not sent an answer key, say, "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

Let's get started.

Burn Injury Follow-up

1. Since your last interview, have you received psychological therapy or counseling due to your burn injury? **pyschther**

- 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.

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*)

- 1. No services (*Interviewer Instructions: skip to #10, surgery item, on page 6*)

services__1

- 2. Occupational therapy services__2
- 3. Physical therapy services__3
- 4. Speech language pathology services__4
- 5. Social work services__5
- 6. Psychological services services__6
- 7. Vocational services services__7

- 88. Declined to answer/Refused
- 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 #10, 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? _____ (*fill in # of sessions*) (*Code 77 for N/A—no services received, 88 for declined to answer/refused, and code 99 for unknown number of sessions*) **numserv**

Added in 2015

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

5. Burn center?

- 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? **surgery_fu**

- 1. Yes
- 2. No (*Interviewer Instructions: skip to Demographics on page 8*)
- 99. Don't know (*Interviewer Instructions: skip to Demographics on page 8*)

- 88. Declined to answer/Refused

New coding for 88/99 added in 2015

Interviewer Instructions: Continue with these questions 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 (*Interviewer Instructions: skip to Demographics on page 8*)
- 99. Don't know (*Interviewer Instructions: skip to Demographics on page 8*)

- 88. Declined to answer/Refused

Added in 2015

Interviewer Instructions: If the participant had surgeries only at the BMS center (ie, they said yes to #10 above and no to #11 above), fill in number 12 and 13 below, about number of surgeries and types of surgeries (and the amputation section, if applicable), using the Medical Record and then move on to Demographics on page 8. If yes to #11 (participant had burn related surgeries outside the BMS center), continue with questions #12 and #13, and indicate that the data was obtained using self-report.

Interviewer Instructions: Continue with these questions if the participant had burn related surgeries outside the BMS center. To help them clarify, say, "We'd like to know how any procedures you had that involved anesthesia, but were for something other than a dressing or cast change. Can you remember?"

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.

9. How many surgeries did you have, including those outside of [*name the BMS center*]?
_____ (code 77 for N/A—no surgery and code 99 for unknown number of surgeries)

num surg (added in 2015)

Source of number of surgeries: Self-report -1 Medical record-2

src_numsurg (77—Not applicable (no surgeries))

10. Which burn related surgeries have you had since your last interview?

(Choose all that apply)

- 1. Surgery for open wounds **surgtype__1** **surgtype__88**
- 2. Surgery for joint contractures **surgtype__2** 99. Unknown **surgtype__99**
- 3. Surgery for scar management **surgtype__3**
- 4. Amputation **surgtype__4** (*Interviewer Instructions: if the participant indicates he/she has had surgery for amputation go on to the Amputation section below. If not, skip to Demographics on page 8*)
- 5. Other **surgtype__5** (if so, what? _____ **otrsurg** _____)
- 77. Not applicable (no surgery) **surgtype__77**

- 88. Declined to answer/Refused

0=not checked
1=checked

Added in 2015

Source of type of surgeries: Self-report -1 Medical record-2
src_surgtype (77—Not applicable (no surgeries))

Amputations

Interviewer Instructions: if the participant hasn't had surgery for amputation, skip to Demographics on page 8. Fill out this information using the medical record unless the amputation was performed outside the BMS center.

1. Have you had an upper extremity amputation due to burn injury since your last interview?
(Choose all that apply) *Interviewer Instructions: ask as open ended and then mark the correct response.*

1. No amputfu1__1; 0=not checked; 1=checked
2. Yes, above elbow right amputfu1__2; 0=not checked; 1=checked
3. Yes, above elbow left amputfu1__3; 0=not checked; 1=checked
4. Yes, above elbow bilateral amputfu1__4; 0=not checked; 1=checked
5. Yes, below elbow right amputfu1__5; 0=not checked; 1=checked
6. Yes, below elbow left amputfu1__6; 0=not checked; 1=checked
7. Yes, below elbow bilateral amput1__7; 0=not checked; 1=checked
8. Yes, digits only right numudgtrfu____(fill in # of digits) (Thumb amputated? thumbrfu
1-Yes 2-No, 99-Unknown) amputfu1__8; 0=not checked; 1=checked
9. Yes, digits only left numudgtlfu____(fill in # of digits) (Thumb amputated?
thumblfu 1-Yes 2-No, 99-Unknown) amputfu1__9; 0=not checked; 1=checked
10. Yes, digits only bilateral numudgtbfu____(fill in # of digits) (Thumbs amputated?
thumbbfu 1-Yes 2-No, 99-Unknown) amputfu1__10; 0=not checked; 1=checked

Notes:

New variable added with new Forms in 2015

88. Declined to answer/Refused--
amputfu1__8899. Unknown amputfu1__99

2. Have you had a lower extremity amputation due to burn injury since your last interview?
(Choose all that apply) *Interviewer instructions: ask as open ended and then mark the correct response.*

1. No amputfu2__1; 0=not checked; 1=checked
2. Yes, above knee right amputfu2__2; 0=not checked; 1=checked
3. Yes, above knee left amputfu2__3; 0=not checked; 1=checked
4. Yes, above knee bilateral amputfu2__4; 0=not checked; 1=checked
5. Yes, below knee right amputfu2__5; 0=not checked; 1=checked
6. Yes, below knee left amputfu2__6; 0=not checked; 1=checked
7. Yes, below knee bilateral amputfu2__7; 0=not checked; 1=checked
8. Yes, digits only right numldgtrfu____(fill in # of digits) amputfu2__8; 0=not
checked; 1=checked
9. Yes, digits only left numldgtlfu____(fill in # of digits) amputfu2__9; 0=not
checked; 1=checked
10. Yes, digits only bilateral numldgtbfu____(fill in # of digits) amputfu2__10;
0=not checked; 1=checked
11. Transmetatarsal right (partial foot amputation right) amputfu2__11; 0=not checked;
1=checked
12. Transmetatarsal left (partial foot amputation left) amputfu2__12; 0=not checked;
1=checked

13. Transmetatarsal bilateral (partial foot amputation bilateral) **amputfu2__13**; 0=not checked; 1=checked

Notes:

New variable added with new Forms in 2015

88. Declined to answer/Refused

amputfu2__88

99. Unknown

amputfu2__99

Source of amputation data: Self-report Medical record

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	2	3	4	5	6	7
<i>Not at all</i>	<i>To a very small extent</i>	<i>To a small extent</i>	<i>To a moderate extent</i>	<i>To a fairly great extent</i>	<i>To a great extent</i>	<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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Hearing? chcself2, chcself2a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Learning and understanding? chcself3, chcself1a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. Controlling emotions or behavior? chcself5, chcself5a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. with Seizures or epilepsy? chcself6, chcself6a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. with Teeth and gums? chcself8, chcself8a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. with Type 1 or Type 2 diabetes? chcself10, chcself10a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. with Growth? chcself11, chcself11a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Sleeping? chcself12, chcself12a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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,	<input type="checkbox"/> Yes=1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

chcself13a	<input type="checkbox"/> No=0								88 / 99
14. with Breathing (eg asthma)? chcself14, chcself14a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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"/> Yes=1 <input type="checkbox"/> No=0	<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

You won't need your answer key for this section. I'll tell you when to use it next.

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

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

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

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

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

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

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

1. Yes
2. No
88. Declined to answer/Refused
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. bodyim_1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I think people would not want to touch me. bodyim_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I feel unsure of myself among strangers. bodyim_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Changes in my appearance have interfered with my relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

bodyim_4					
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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
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
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		88 / 99

around you and what is around you) cpss_16				<input type="checkbox"/>
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

PROMIS Anger

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

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I felt upset pr714r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt fed up pr5045r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I was so angry I felt like throwing something pr2319ar1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I was so angry I felt like yelling at somebody pr2581r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. When I got mad, I stayed mad proang_6 (not administered on spanish forms)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88 / 99

88 / 99

88 / 99

88 / 99

88 / 99

88 / 99

PROMIS 25

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

Physical function mobility

In the past 7 days...	4=with no trouble	3=with a little trouble	2= With some trouble	1= With a lot of trouble	0=Not able to do
1. I could do sports and exercise that other kids my age could do pr235r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I could get up from the floor pr4124r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I could walk up stairs without holding on to anything pr2707r2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I have been physically able to do the activities I enjoy most pr5023r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88 / 99

88 / 99

88 / 99

88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I felt nervous pr713r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt worried pr5044r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88 / 99

88 / 99

88 / 99

4. I worried when I was at home pr3459br1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
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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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I felt lonely pr711r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I felt sad pr228r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. It was hard for me to have fun pr3952ar2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I got tired easily pr2876r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I was too tired to do sports or exercise pr4241r2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. I was too tired to enjoy the things I like to do pr4196r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I was able to count on my friends pr5058r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. My friends and I helped each other out pr5055r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Other kids wanted to be my friend pr233r2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

2. It was hard for me to pay attention when I had pain pr9004	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. It was hard for me to run when I had pain pr2045r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. It was hard for me to walk one block when I had pain pr2049r1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. I felt angry when I was itching bmsitch_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. I had trouble doing schoolwork when I was itching bmsitch_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. It was hard for me to pay attention when I was itching bmsitch_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. It was hard for me to have fun when I was itching bmsitch_5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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. <i>ptgic_1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
2. I can now handle big problems better than I used to. <i>ptgic_2</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
3. I know what is important to me better than I used to. <i>ptgic_3</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
4. I understand how God works better than I used to. <i>ptgic_4</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
5. I feel closer to other people (friends or family) than I used to. <i>ptgic_5</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
6. I appreciate (enjoy) each day more than I used to. <i>ptgic_6</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
7. I now have a chance to do some things I couldn't do before. <i>ptgic_7</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
8. My faith (belief) in God is stronger than it was before. <i>ptgic_8</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
9. I have learned that I can deal with more things than I thought I could before. <i>ptgic_9</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused
10. I have new ideas about how I want things to be when I grow up. <i>ptgic_10</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88/Refused

DEMOGRAPHICS

Next I have some general questions about you.

Interviewer instructions: Record participant's height and weight in pounds and feet/inches

1. What is your current weight? (lbs) _____ (code 9999 for unknown) **htfu**
Added to adult data collection in 2015

2. What is your current height? (feet/inches) _____ (code 9999 for unknown) **wtfu**
Added to adult data collection in 2015

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

- | | |
|---|---|
| 1. <input type="checkbox"/> House | 88. <input type="checkbox"/> Declined to answer/Refused |
| 2. <input type="checkbox"/> Apartment | 99. <input type="checkbox"/> Unknown |
| 3. <input type="checkbox"/> Mobile home | |
| 4. <input type="checkbox"/> Institution | |
| 5. <input type="checkbox"/> Homeless | |

6. Other

4. What is your current zip code? _____ **zipfu** (Code 99999 for unknown, code 00000 for Mexico)

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** 88. Declined to answer/Refused
- 5. Other relative (siblings, grandparents) **livingafu__5** **livingafu__88**
- 6. Others, not part of family **livingafu__6** 99. Unknown
- 7. Guardian **livingafu__7** **livingafu__99**

For all variables, 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 #9 below 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). **aprogfu**

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

- 1. Same program full time 88. Declined to answer/Refused
- 2. Same program part time 99. Unknown
- 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

Interviewer Instructions: Skip to #10 on the next page if the participant is going to school.

8. If you aren't going to school, why not? **whynotfu**

- 1. Burn related 88. Declined to answer/Refused
- 2. Other medical problems 99. Unknown
- 4. Emotional/social
- 5. Legal/jail
- 6. Substance abuse
- 7. Personal choice
- 8. Other
- 77. Not applicable (going to school)

Interviewer instructions: Skip #9 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.

9. What was your first date to return to work/school since injury?: _____/_____/_____

Entered into the patient status form: returndat

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 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 | |
| 66. <input type="checkbox"/> Other | |

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

- | | |
|---|---|
| 1. <input type="checkbox"/> I am not receiving disability income (<i>Interviewer Instructions: skip to #13, below, if the participant is not receiving disability income</i>) | 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 _____ 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. <input type="checkbox"/> Yes, I am receiving disability income due to my burn injury |
| 2. <input type="checkbox"/> No, I am not receiving disability income due to my burn injury |
| 77. <input type="checkbox"/> Not applicable (not receiving disability income) |
| 99. <input type="checkbox"/> Unknown |

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

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

14. Do you currently have any psychological issues, such as depression or anxiety? psychisfup

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

Variable names appear in red.

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: _____

FT2. 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. 1 year follow-up
- 3. 2 year 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

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

- 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 **Option 14 added with new forms in 2015**

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.

Answer Key:

If the participant was sent or was given an answer key, say, "Do you have your answer key in front of you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. If the participant was not sent an answer key, go to the second bullet below.

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*

- If the answer is no and this is a telephone interview, or if the participant was not sent an answer key, say, "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."
- If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."

Let's get started.

Burn Injury Follow-up

I have some questions related to your child's burn injury...

1. 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

2. Since your last interview, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? **peersupprx**

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.

- 1. Yes
- 2. No
- 77. Not applicable
- 99. Don't know

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

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

1. No services (*Interviewer Instructions: skip to #10, surgery item, on page 6*)

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 **servicesprx__7**

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

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 #7, surgery item, on the next page.

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

4. How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? _____ (fill in # of sessions) (Code 77 for N/A—no services received and code 99 for unknown number of sessions) **numservprx**

Since your last interview, where did your child receive his/her outpatient occupational or physical burn therapy? **ther_brn_ctrprx**

5. This clinical burn center? 88. Declined to answer/Refused
1. Yes 99. Unknown
2. No
77. Not applicable (no OT/PT received)

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

7. Since your last interview [provide date], has your child had any burn related surgeries? 88. Declined to answer/Refused
surgery_fuprx
1. Yes
2. No (*Interviewer Instructions: skip to Demographics on page 8*)
99. Don't know (*Interviewer Instructions: skip to Demographics on page 8*)

Interviewer Instructions: Continue with these questions if the participant had burn related surgeries

8. Has your child had any burn-related surgeries outside of [name the BMS center]? 88. Declined to answer/Refused
surgoutprx
1. Yes 88. Declined to answer/Refused
2. No (*Interviewer Instructions: skip to Demographics on page 8*)
99. Don't know (*Interviewer Instructions: skip to Demographics on page 8*)

*Interviewer Instructions: If the child had surgeries only at the BMS center (ie, they said **yes to #7** above and **no to #8** above), fill in number 9 and 10 below, about number of surgeries and types of surgeries (and the amputation section, if applicable), using the Medical Record and then move on to Demographics on page 7. If **yes to #8** (child had burn related surgeries outside the BMS center), continue with questions #9 and #10, and indicate that the data was obtained using self-report.*

*Interviewer Instructions: Continue with these questions if the child had burn related surgeries outside the BMS center. To help them clarify, say, "We'd like to know how any procedures your child had that involved anesthesia, but were for something other than a dressing or cast change. Can you remember?" **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.*

9. How many surgeries did your child have, including those outside of [name the BMS center]? _____ (code 77 for N/A—no surgery and code 99 for unknown number of surgeries)
numsurgprx
Source of number of surgeries: Self-report-1 Medical record-2
src_numsurgprx

13. Which burn related surgeries has your child had since your last interview?

(Choose all that apply)

- 1. Surgery for open wounds **surgtypeprx__1**
- 2. Surgery for joint contractures **surgtypeprx__2**
- 3. Surgery for scar management **surgtypeprx__3**
- 4. Amputation **surgtypeprx__4**
- 5. Other **surgtypeprx__5** (if so, what? _____ **otrsurgprx_____**)
- 77. Not applicable (no surgery) **surgtypeprx__77**
- 88. Declined to answer/Refused **surgtypeprx__88**
- 99. Unknown **surgtypeprx__99**

0=not checked

1=checked

Added in 2015

Source of type of surgeries: Self-report-1 Medical record-2
src_surgtypeprx

Amputations

1. Has your child had an upper extremity amputation due to burn injury since your last interview?

(Choose all that apply) *Interviewer Instructions: ask as open ended and then mark the correct response.*

- 1. No **amputfu1prx__1**; 0=not checked; 1=checked
- 2. Yes, above elbow right **amputfu1prx __2**; 0=not checked; 1=checked
- 3. Yes, above elbow left **amputfu1prx __3**; 0=not checked; 1=checked
- 4. Yes, above elbow bilateral **amputfu1prx __4**; 0=not checked; 1=checked
- 5. Yes, below elbow right **amputfu1prx __5**; 0=not checked; 1=checked
- 6. Yes, below elbow left **amputfu1prx __6**; 0=not checked; 1=checked
- 7. Yes, below elbow bilateral **amputfu1prx __7**; 0=not checked; 1=checked
- 8. Yes, digits only right **numudgtrfuprx _____**(fill in # of digits) (Thumb amputated? **thumbrfu prx**
1-Yes 2-No, 99-Unknown) **amputfu1prx __8**; 0=not checked; 1=checked
- 9. Yes, digits only left **numudgtlfuprx _____**(fill in # of digits) (Thumb amputated? **thumblfuprx** 1-Yes 2-No, 99-Unknown) **amputfu1prx __9**; 0=not checked; 1=checked
- 10. Yes, digits only bilateral **numudgtbfuprx _____**(fill in # of digits) (Thumbs amputated? **thumbbfuprx** 1-Yes 2-No, 99-Unknown) **amputfu1prx __10**; 0=not checked; 1=checked

Notes:

New variable added with new Forms in 2015

88. Declined to answer/Refused-- **amputfu1prx __88**

99. Unknown **amputfu1prx __99**

2. Has your child had a lower extremity amputation due to burn injury since your last interview?

(Choose all that apply) *Interviewer instructions: ask as open ended and then mark the correct response.*

- 1. No **amputfu2prx __1**; 0=not checked; 1=checked
- 2. Yes, above knee right **amputfu2prx __2**; 0=not checked; 1=checked
- 3. Yes, above knee left **amputfu2prx __3**; 0=not checked; 1=checked
- 4. Yes, above knee bilateral **amputfu2prx __4**; 0=not checked; 1=checked
- 5. Yes, below knee right **amputfu2prx __5**; 0=not checked; 1=checked
- 6. Yes, below knee left **amputfu2prx __6**; 0=not checked; 1=checked
- 7. Yes, below knee bilateral **amputfu2prx __7**; 0=not checked; 1=checked
- 8. Yes, digits only right **numldgtrfuprx _____**(fill in # of digits) **amputfu2prx__8**;
0=not checked; 1=checked

- 9. Yes, digits only left numldgtlfuprx _____ (fill in # of digits) amputfu2__9; 0=not checked; 1=checked
- 10. Yes, digits only bilateral numldgtbfuprx _____ (fill in # of digits) amputfu2__10; 0=not checked; 1=checked
- 11. Transmetatarsal right (partial foot amputation right) amputfu2prx__11; 0=not checked; 1=checked
- 12. Transmetatarsal left (partial foot amputation left) amputfu2prx__12; 0=not checked; 1=checked
- 13. Transmetatarsal bilateral (partial foot amputation bilateral) amputfu2prx__13; 0=not checked; 1=checked

Notes:

New variable added with new Forms in 2015

88. Declined to answer/Refused

amputfu2prx__88

99. Unknown

amputfu2prx__99

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 | 2 | 3 | 4 | 5 | 6 | 7 |
| <i>Not at all</i> | <i>To a very small extent</i> | <i>To a small extent</i> | <i>To a moderate extent</i> | <i>To a fairly great extent</i> | <i>To a great extent</i> | <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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. with Type 1 or Type 2 diabetes?	<input type="checkbox"/> Yes=1	<input type="checkbox"/>	<input type="checkbox"/>	<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.

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NewMSID _____

chcprox10, chcprox10a	<input type="checkbox"/> No=0								
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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? chcprox13, chcprox13a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox14, chcprox14a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox15, chcprox15a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox16, chcprox16a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox17, chcprox17a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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? chcprox18, chcprox18a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Itching bmsitch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Pain Medication

You won't need your answer key for this section. I'll tell you when to use it next.

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 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?

smedprx

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

DEMOGRAPHICS

Next I have some general questions about your child.

Interviewer instructions: Record participant's height and weight in pounds and feet/inches

1. What is your child's current weight? (lbs)_____ (code 9999 for unknown) **wtfuprx**

2. What is your child's current height? (feet/inches)_____ (code 9999 for unknown) **htfuprx**

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

- 1. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 5. Homeless
- 6. Other
- 88. Declined to answer/Refused
- 99. Unknown

4. What is your child's current zip code? _____ **zipfuprx**
(Code 99999 for unknown, code 00000 for Mexico)

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
- 99. Unknown

For all variables, 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 #8 below if this is a 5, 10, or 15 year follow-up.*)
- 2. Not in School (*Interviewer Instructions: Skip to #10 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
- 88. Declined to answer/Refused
- 99. Unknown

- 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

Interviewer Instructions: Skip to #10 on the next page if the child is going to school. **whynotfuprx**

8. If your child isn't going to school, why not?

- 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

Interviewer instructions: Skip #9 and move on to #10 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.

9. 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

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.

- 0. Preschool completed
- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 77. Not applicable (child is too young for school)
- 88. Declined to answer/Refused
- 99. Unknown

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

6. Other _____ **disincfupprx**_____

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 currently have any psychological issues, such as depression or anxiety? **psychisfupprx**

- 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." **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
- 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

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)

16. 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
- 4. Worker's compensation (L&I)
- 5. HMO/PPO/Pre-paid/Managed Care
- 6. Champus/Tri-Care
- 7. Self-pay
- 8. Indigent (public support; charity care)
- 88. Declined to answer/Refused
- 99. Unknown

- 9. VA
- 10. Other
- 11. Philanthropy (private support)
- 77. Not applicable (no burn care costs)

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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. This child thinks that people would not want to touch him/her. bodyimp_2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. This child feels unsure of himself/herself among strangers. bodyimp_3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Changes in this child's appearance have interfered with his/her relationships. bodyimp_4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

PEDI Mobility

Interviewer instructions: If the child is under 3 years old, you are done with the survey once the parent answers two of the PEDI mobility questions in a row with "Unable". If the child is between 3-7, administer the rest of the survey once the participant answers two questions in a row with "Unable". If the parent does not answer two of the PEDI mobility questions in a row with "Unable", but the child is 3 or older, administer the rest of the survey once all the PEDI mobility questions have been asked.

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.)

Please choose which response best describes your child's ability in the following activities.	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
--	--------------------------	--------------------------	--------------------------	--------------------------	---------

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, below.

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: _____

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 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. pedproxdep03	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. Cries a lot. pedproxdep05	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Seems lonely. pedproxdep06	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. Withdraws from peer activities. pedproxdep13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99

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.	<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.

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NewMSID _____

papxy066						
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

NIH Toolbox Positive Affect (for children ages 3-7)

In the past 7 days:

Interviewer Instructions: If the participant isn't sure how to answer these questions and asks "about what?", you can use the prompt, "These questions are asking about your child's life in general."

	1= Not at all	2= A little bit	3= Some what	4= Quite a bit	5= Very much	
1. My child was cheerful. papxy007_3to7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
2. My child was enthusiastic. papxy019_3to7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. My child was interested. papxy021_3to7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
4. My child was confident. papxy022_3to7	<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: _____

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 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; 0=not checked; 1=checked
- 2. Medical Record Abstraction Form status__2; 0=not checked; 1=checked
- 3. Review of Systems Checklist Form status__3; 0=not checked; 1=checked
- 4. 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.

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.

Answer Key:

If the interview is over the phone and the participant was sent an answer key, say, "Did you receive your answer key that we sent you? The answer key shows the responses you can choose from when you answer the questions I'll be asking. If you have it, the interview will go a little faster and will be a little easier to follow. *If the participant was not sent an answer key, go to the second bullet below.*

- *If the answer is yes, say, "Great. I will tell you when to use the answer key." Answer key prompts are underlined throughout the interview. However, answer key prompts are not boxed and shaded.*
- *If the answer is no, or if the participant was not sent an answer key, say "Do you have access to a computer right now? I could email the answer key to you right now so you have it while we go over the survey."*
- *If the participant doesn't have access to a computer or doesn't want it emailed, say, "That's okay, we can also go through the survey without the answer key. I will guide you through the questions."*

If the interview is in person and the participant has an answer key, say, "The answer key I gave you shows the responses you can choose from when you answer the questions I'll be asking. I will tell you when to use the answer key.

Let's get started. The first section is about your child's current health.

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 | 2 | 3 | 4 | 5 | 6 | 7 |
| <i>Not at all</i> | <i>To a very
small extent</i> | <i>To a small
extent</i> | <i>To a moderate
extent</i> | <i>To a fairly
great extent</i> | <i>To a great
extent</i> | <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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Hearing? chcprox2, chcprox2a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
11. with Growth? chcprox11, chcprox11a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88 / 99
12. Sleeping? chcprox12, chcprox12a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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? chcprox13, chcprox13a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox14, chcprox14a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox15, chcprox15a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)? chcprox16, chcprox16a	<input type="checkbox"/> Yes=1 <input type="checkbox"/> No=0	<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)?	<input type="checkbox"/> Yes=1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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"/>	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. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 5. Homeless
- 6. Other
- 88. Declined to answer/Refused
- 99. Unknown

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)

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*
 - 7. Guardian *livingaprx__7*
 - 88. Declined to answer/Refused
 - 99. Unknown
- 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 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. 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)? **physprobprx**

- 1. Yes
- 2. No

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

7. Before the burn, did your child have any psychological issues, such as depression or anxiety? **psychisprx**

- 1. Yes
- 2. No

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

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

- 1. Yes
- 2. No

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

Demographics

Interviewer Instructions: Use medical record for #1 and #2. 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. If disposition (#2, below) is not clear on Medical Record, clarify with parent proxy

1. What were the circumstances of your child’s burn injury? **circinj**

Interviewer instructions: Ask this as open-ended, using, “Can you tell me about the circumstances of your child’s burn injury?” if necessary. If needed, in order to probe for location, ask “Did it happen at work, at home, or somewhere else?” If someone else caused it, in order to probe for intentionality, ask “Was it intentional?” If the child caused it, be cautious about probing for intentionality, and, if okay, ask “Did he/she mean to?”

- 1. Non-intentional employment related (Not applicable for pediatrics)
- 2. Non-intentional non-recreation related (*Interviewer Instructions: choose this category if the burn involved an accident or fire at home that was non-recreational in nature*)
- 3. Non-intentional recreation
- 4. Non-intentional non-specified (*Interviewer Instructions: 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
- 88. Declined to answer/Refused
- 99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

2. Where will your child go after he/she is discharged from the hospital for his/her burn? (Choose only one) **disposn**

- 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 associated with this clinic/hospital)
- 9. Discharged, institution
- 10. Discharged, drug/alcohol treatment center
- 11. Discharged, shelter
- 12. Discharged, street
- 14. Other
- 88. Declined to answer/Refused
- 99. Unknown

Stored in Medical Record Abstraction Form—this variable appears on the Form I in case self-report is better source of data.

1. What is your child’s race and/or ethnicity? (Choose only one) **ethncity**

- 1. White, non-Hispanic (including Middle Eastern and Indian)
- 2. Black, non-Hispanic
- 3. Hispanic
- 4. Pacific Islander
- 5. Asian
- 6. Native American
- 7. Multi-Racial
- 8. Other
- 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. After your child’s hospital discharge, where will he/she be living? (Choose only one)

dislivsitprx

- 1. House
- 2. Apartment
- 3. Mobile home
- 4. Institution
- 5. Homeless
- 6. Other
- 88. Declined to answer/Refused
- 99. Unknown

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

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

- 4. Parent or step-parent **livhisdisprx__4**
- 5. Other relative (siblings, grandparents) **livhisdisprx__5**
- 6. Others, not part of family **livingprx__6**
- 7. Guardian **livhisdisprx__7**

The previous variable “livhsdis” was changed with the move to the new forms in 2015 to include options for choose all that apply. Clarification was also added to “other relative” option to include “siblings, grandparents”, “other”, to include “not part of family”.

88. Declined to answer/Refused **livhisdisprx__88**

4. How many years of education has your child cor99. Unknown **livhisdisprx__99**

Interviewer instructions: Ask the question as open-ended

- 0. Preschool completed
- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 88. Declined to answer/Refused
- 99. Unknown

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)? _____ number field _____ hincnumpreprx
(Code 777 if not applicable; Code 888 if declined to answer/refused; Code 999 if missing/unknown)

Interviewer instructions: Fill in the number if the participant gives this information. Provide the following categories as options if the participant hesitates or can’t answer. If the person isn’t sure or doesn’t want to give a number, say “Let me read you some broad income categories. Please take your best guess if you don’t know the exact number. Here they are...”

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

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)

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

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

7. Who is the primary sponsor of your child’s care at hospital discharge? That is, who is paying for the majority of your child’s burn care costs? (Choose only one) sponsprx

- 1. Medicare
- 2. Medicaid (DSHS)
- 3. Private insurance
- 4. Worker’s compensation (L&I)
- 5. HMO/PPO/Pre-paid/Managed Care
- 6. Champus/Tri-Care
- 7. Self-pay
- 8. Indigent (public support; charity care)
- 9. VA
- 88. Declined to answer/Refused
- 99. Unknown

- 10. Other
- 11. Philanthropy (private support)

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: _____

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? **ci2prx_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**

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

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

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
- 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

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: _____