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.

BMS Patient Status Form Codebook

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 ethncity

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_ethncity
1. ☐ Medical record
2. ☐ Self report

The following questions are only for patients who were <u>alive at discharge and consented</u> 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

Today's Date: ___ ___ / ___ ___ / ___ ___

NewMSID   _____

<u>*Instructions to BMS staff for use of this form*</u>: *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/flame
- 2. ☐ Scald
- 3. ☐ Contact with hot object
- 4. ☐ Grease
- 5. ☐ Tar
- 6. ☐ Chemical
- 7. ☐ Hydrofluoric acid
- 8. ☐ Electricity
- 9. ☐ Radiation
- 10. ☐ UV light
- 11. ☐ Other burn
- 15. ☐ Flash burn
- 99. ☐ Unknown

Source of MR1: src_pretiol
- 1. ☐ Medical record
- 2. ☐ Self report

MR2. Space/place of burn injury: placeinj
- 1. ☐ Closed/indoors
- 2. ☐ Open/outdoors
- 99. ☐ Unknown

Source of MR2: src_placeinj
- 1. ☐ Medical record
- 2. ☐ Self report

BMS Form I Medical Record Abstraction Codebook

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

BMS Form I Medical Record Abstraction Codebook

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

BMS Form I Medical Record Abstraction Codebook

NewMSID_____

MR13. Shoulder/Upper Arm/Elbow suebrn (variable name prior to 1/15, with arm data, was armbrn)
- 1. ☐ Right   3. ☐ Bilateral   99. ☐ Unknown
- 2. ☐ Left   4. ☐ None

MR14. Forearm (includes wrist) farmbrn (variable name prior to 1/15, with arm data, was armbrn)
- 1. ☐ Right   3. ☐ Bilateral   99. ☐ Unknown
- 2. ☐ Left   4. ☐ None

MR15. Hand handbrn
- 1. ☐ Right   3. ☐ Bilateral   99. ☐ Unknown
- 2. ☐ Left   4. ☐ None

MR16. Leg legbrn
- 1. ☐ Right   3. ☐ Bilateral   99. ☐ Unknown
- 2. ☐ Left   4. ☐ None

MR17. Foot footbrn
- 1. ☐ Right   3. ☐ Bilateral   99. ☐ Unknown
- 2. ☐ Left   4. ☐ None

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) trnkgrft
- 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

4

BMS Form I Medical Record Abstraction Codebook

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): tbsabrn_____ (XX.X)
(*code 999 for unknown*)

MR27.Total body surface area grafted (percent): tbsagrft_____ (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

BMS Form I Medical Record Abstraction Codebook

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 numudgtr___(fill in # of digits) (Thumb amputated? thumbr ☐
   1-Yes ☐ 2-No, 99-Unknown) amput1___7; 0=not checked; 1=checked
8. ☐ Yes, digits only left numudgtl_____(fill in # of digits) (Thumb amputated? thumbl
   ☐ 1-Yes ☐2-No, 99-Unknown) amput1___8; 0=not checked; 1=checked
9. ☐ Yes, digits only bilateral numudgtb _____(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 numldgtr _____(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

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: ___ ___ / ___ ___ / ___ ___   disdcdate
(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."

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

BMS Adult Codebook Form I
NewMSID_____

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.

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

BMS Adult Codebook Form I
NewMSID_____

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

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

BMS Adult Codebook Form I

NewMSID_____

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

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

BMS Adult Codebook Form I
NewMSID_____

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	☐	☐	☐	☐	☐	☐	☐	88/Refused 99/Unknown
2. In the 4 weeks before my burn, the conditions of my life were excellent: sl2_pre	☐	☐	☐	☐	☐	☐	☐	88/Refused 99/Unknown
3. In the 4 weeks before my burn, I was satisfied with my life: sl3_pre	☐	☐	☐	☐	☐	☐	☐	88/Refused 99/Unknown
4. In the 4 weeks before my burn, I had gotten the important things I wanted in life: sl4_pre	☐	☐	☐	☐	☐	☐	☐	88/Refused 99/Unknown

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

BMS Adult Codebook Form I
NewMSID_____

| 5. In the 4 weeks before my burn, if I could have lived my life over, I would have changed almost nothing: sl5_pre | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 88/Refused 99/Unknown |

CIQ: 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. ☐ Yourself alone
    2. ☐ Yourself and someone else
    3. ☐ Someone else

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

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

2: Shopping ci3_pre

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

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

3: Leisure activities such as movies, sports, and restaurants. ci4_pre

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

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

4: Visiting friends or relatives ci5_pre

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

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

During the 4 weeks before your burn:

5: When you participated in leisure activities did you usually do this alone or with others? ci6_pre

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

    1. ☐ Mostly alone
    2. ☐ Mostly with friends who have burn injuries *(N/A for Form I)*
    3. ☐ Mostly with family members
    4. ☐ Mostly with friends who do not have burn injuries
    5. ☐ With a combination of family and friends

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

    1. ☐ Yes
    2. ☐ No

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

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

BMS Adult Codebook Form I
NewMSID_____

PHQ-9 #9: PRE-BURN

Interviewer Instructions: Be informed of your center's protocol for suicidal ideation, and follow those procedures if the participant 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 <u>two weeks before your burn</u>, 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 <u>before your burn injury</u>? 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

7

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

BMS Adult Codebook Form I
NewMSID_____

2. The following questions are about activities you might do during a typical day. Did **your health limit you** in these activities <u>before your burn injury</u>? 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. <u>During the 4 weeks before your burn</u>, did you have any of the following problems with your work or other regular daily activities **as a result of your physical health?**

vr12pre3a	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.	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. <u>During the 4 weeks before your burn</u>, 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)?

vr12pre4a	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.	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. <u>During the 4 weeks before your burn</u>, 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	88/Refused 99/Unknown
1	2	3	4	5	

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

6. How much of the time <u>during the 4 weeks before your burn</u>:

BMS Adult Data Dictionary Form I

NewMSID_____

	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 vr12pre6c **downhearted and blue**?	1	2	3	4	5	6	88/Refused 99/Unknown

7. <u>During the 4 weeks before your burn</u>, 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
    0=not checked

    88. ☐ Declined to answer/Refused livinga___88
    99. ☐ Unknown livinga___99

Version 3/2015

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_____

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   88. ☐ Declined to answer/Refused
  3. ☐ Divorced   99. ☐ Unknown
  4. ☐ Widowed
  5. ☐ Single (not married)

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

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

hinccatpre
  1. ☐ Less than $25,000   88. ☐ Declined to answer/Refused
  2. ☐ $25,000-$49,999   99. ☐ Unknown
  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)

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_____

10

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_____

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   *Instructions: skip to #10, below*
    5. ☐ Volunteer
    6. ☐ Retired
    88. ☐ Declined to answer/Refused
    99. ☐ Unknown   66-"Not working" on old forms
Old variable was named "employ".   77-Not applicable due to age

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

9. Before your burn, about how many <u>hours a week</u> 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   88. ☐ Declined to answer/Refused
            2. ☐ $25,000-$40,999   99. ☐ Unknown
            3. ☐ $41,000-$55,999
            4. ☐ $56,000-$70,999

                                                                11

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_____

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   88. ☐ Declined to answer/Refused
    2. ☐ Not in school   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 <u>was</u> 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)*   88. ☐ Declined to answer/Refused
    2. ☐ Medical problems other than your burn injury.   99. ☐ Unknown
    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
    77. ☐ Not applicable (working or going to school) Response option added with 2015 forms

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

14. 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

15. Did you receive psychological therapy or counseling in the last 12 months? psychtr
    1. ☐ Yes   88. ☐ Declined to answer/Refused
    2. ☐ No   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

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_____

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 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

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

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

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	88/Refused 99/Unknown
1	2	3	4	5	

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. <u>You don't need the response key for this section.</u>
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 (**E**ye-opener) to steady your nerves or to get rid of a hangover? ☐ Yes (1) ☐ No (0)

CAGE Drug use:

Interviewer Instructions: If clarification is needed, say, "We are interested in learning more about use of drugs like 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 (**E**ye-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 <u>since your burn injury</u>.

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. ☐ Not present
2. ☐ Mild
3. ☐ Moderate
4. ☐ Severe
5. ☐ Unbearable
77. ☐ Not applicable (no itching)

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

3. Has your itching related to the burn injury gotten better or worse <u>since the injury</u>? itch3_dis

1. ☐ Completely resolved
2. ☐ Much better, but still present
3. ☐ Little bit better, but still present
4. ☐ Unchanged
5. ☐ Getting worse
77. ☐ Not applicable (no itching)

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

4. Please rate the impact of your <u>current</u> itching on your sleep**:** itch4_dis

1. ☐ Never affects sleep
2. ☐ Occasionally delays falling asleep
3. ☐ Frequently delays falling asleep
4. ☐ Delays falling asleep and occasionally wakes me up at night
5. ☐ Delays falling asleep and frequently wakes me up at night
77. ☐ Not applicable (no itching)

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

DEMOGRAPHICS

This is the last section of the survey.

Interviewer Instructions: Use medical record for #1and #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

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

BMS Adult Codebook Form I
NewMSID_____

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   88. ☐ Declined to answer/Refused
3. ☐ Hispanic   99. ☐ Unknown
4. ☐ Pacific Islander
5. ☐ Asian
6. ☐ Native American
7. ☐ Multi-Racial
8. ☐ 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. ☐ House   88. ☐ Declined to answer/Refused
2 ☐ Apartment   99. ☐ Unknown
3. ☐ Mobile home
4. ☐ Institution

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

BMS Adult Codebook Form I
NewMSID_____

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   88. ☐ Declined to answer/Refused livhisdis ___88
2. ☐ Spouse/partner/significant other livhisdis ___2   99. ☐ Unknown livhisdis___99
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

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. Old, archived data was converted to new coding and imported.
Interviewer Instructions: Ask the question as open-ended, and then mark the appropriate response below.

1. ☐ 1 year or less   88. ☐ Declined to answer/Refused
2. ☐ 2 years   99. ☐ Unknown
3. ☐ 3 years
4. ☐ 4 years
5. ☐ 5 years
6. ☐ 6 years
7. ☐ 7 years
8. ☐ 8 years
9. ☐ 9 years
10. ☐ 10 years

11. ☐ 11 or 12 years; no diploma
12. ☐ High school diploma
13. ☐ Work towards Associate's degree
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   88. ☐ Declined to answer/Refused
   2. ☐ Yes   99. ☐ Unknown
   77. ☐ Not applicable (high school diploma or higher)

6. Are you currently receiving <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) disincdis   88. ☐ Declined to answer/Refused
   1. ☐ I am not receiving disability income   99. ☐ Unknown
   2. ☐ Social Security Disability
   3. ☐ Private long term insurance disability income
   4. ☐ Supplemental security income (SSI)
   5. ☐ Worker's compensation
   6. ☐ Other ___disincdiso_____

7. Were you ever incarcerated for conviction of a felony? feldis
   1. ☐ No   88. ☐ Declined to answer/Refused
   2. ☐ Yes   99. ☐ Unknown

8. While in school, were you ever classified as a special education student? speducdis
   1. ☐ No   88. ☐ Decline to answer/Refused
   2. ☐ Yes   99. ☐ Unknown

9. Have you ever served in the military? mildis

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: _____

BMS Adult Review of Systems Codebook Form I: <u>Discharge</u>

NewMSID_____

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

BMS Adult Review of Systems Codebook Form I: <u>Discharge</u>

NewMSID_____

13. Swollen feet or legs? swflegdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
14. Swollen hands or arms? swharmdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
15. Difficulty breathing when doing your regular daily activities? difbrergdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
16. Difficulty breathing when exercising? difbreexdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
17. Skin cancer? skincancdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
18. Joint pain? jpaindis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ 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	☐None=0　　☐One=1 ☐More than 1=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
20. Blood clots in legs or lungs? bcleglungdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
21. Cold intolerance? cintoldis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
22. Excessive sweating? exsweatdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ Don't know/Missing=99
23. Difficulty in hot environments? difhotdis	☐ Yes=1　　☐ No=2 ☐ Skipped/Refused=88 ☐ 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

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

BMS Adult Codebook Form II

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.

Version 3/2015

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

BMS Adult Codebook Form II

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

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

Added in 2015

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

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

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

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

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*)
services___1
    2. ☐ Occupational therapy services___2   88. ☐ Declined to answer/Refused
    3. ☐ Physical therapy services___3   services___88
    4. ☐ Speech language pathology services___4   99. ☐ Unknown services___99
    5. ☐ Social work services___5
    6. ☐ Psychological services services___6
    7. ☐ Vocational services services___7
        0=not checked
        1=checked

Added in 2015

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

BMS Adult Codebook Form II

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*)

numsurg (added in 2015)

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

src_numsurg (77—Not applicable (no surgeries)

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

BMS Adult Codebook Form II

13. Which burn related surgeries have you had since your last interview?
(Choose all that apply)   88. ☐ Declined to answer/Refused
    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: 88. ☐ Declined to answer/Refused--
 New variable added with new Forms in 2015   amputfu1___88
                                           99. ☐ Unknown amputfu1___99

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

BMS Adult Codebook Form II

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

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?	☐ Yes	☐ No	☐ Don't know	88/Refused
2. Change in voice?	☐ Yes	☐ No	☐ Don't know	88/Refused
3. Vision problems not corrected by glasses or contact lenses?	☐ Yes	☐ No	☐ Don't know	88/Refused
4. Eyelid problems?	☐ Yes	☐ No	☐ Don't know	88/Refused
5. Excessive tearing of the eyes?	☐ Yes	☐ No	☐ Don't know	88/Refused
6. Difficulty with memory?	☐ Yes	☐ No	☐ Don't know	88/Refused
7. Difficulty with thought processing?	☐ Yes	☐ No	☐ Don't know	88/Refused

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

BMS Adult Codebook Form II

8. Numbness, pins and needles or burning sensations in your burn scar?	☐ Yes	☐ No	☐ Don't know	88/Refused
9. Numbness, pins and needles or burning sensations in your hands?	☐ Yes	☐ No	☐ Don't know	88/Refused
10. Numbness, pins and needles or burning sensations in your feet?	☐ Yes	☐ No	☐ Don't know	88/Refused
11. Trouble with your balance?	☐ Yes	☐ No	☐ Don't know	88/Refused
12. Varicose veins?	☐ Yes	☐ No	☐ Don't know	88/Refused
13. Swollen feet or legs?	☐ Yes	☐ No	☐ Don't know	88/Refused
14. Swollen hands or arms?	☐ Yes	☐ No	☐ Don't know	88/Refused
15. Difficulty breathing when doing your regular daily activities?	☐ Yes	☐ No	☐ Don't know	88/Refused
16. Difficulty breathing when exercising?	☐ Yes	☐ No	☐ Don't know	88/Refused
17. Skin cancer?	☐ Yes	☐ No	☐ Don't know	88/Refused
18. Joint pain?	☐ Yes	☐ No	☐ Don't know	88/Refused
19. Have you been pregnant or fathered a child since your last interview?	☐ Yes	☐ No		88/Refused
20. Blood clots in legs or lungs?	☐ Yes	☐ No	☐ Don't know	88/Refused
21. Cold intolerance?	☐ Yes	☐ No	☐ Don't know	88/Refused
22. Excessive sweating?	☐ Yes	☐ No	☐ Don't know	88/Refused
23. Difficulty in hot environments?	☐ Yes	☐ No	☐ Don't know	88/Refused

Pain Medication

1. In the past month did you take prescription medication for pain on a regular basis? pmed
   ☐ Yes
   ☐ 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
   ☐ Yes
   ☐ 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
   ☐ Yes
   ☐ 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
   ☐ Yes
   ☐ No

4-D Itch scale:

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

During the last two weeks, have you had any itching in the area of your burn, skin grafts, or donor sites? itchscr
   1. ☐ Yes
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown

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

BMS Adult Codebook Form II

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

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

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

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

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

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

	Not applicable =0	Never affects sleep=1	Occasionally 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	☐	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	☐	88 / 99
Housework/errands: itch6	☐	☐	☐	☐	☐	☐	88 / 99
Work/school itch7	☐	☐	☐	☐	☐	☐	88 / 99

Version 3/2015

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

BMS Adult Codebook Form II

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.

<u>**VR-12:**</u>

INSTRUCTIONS: The next questions ask you for your views about your health. This information will keep track of how you feel and how well you are able to do your usual activities.

Answer every question by choosing a response. If you are unsure how to answer a question, please give your answer the best you can.

Interviewer Instructions: Circle one number on each line

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

EXCELLENT	**VERY GOOD**	**GOOD**	**FAIR**	**POOR**
1	2	3	4	5

88/Refused
99/Unknown

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. <u>During the past 4 weeks</u>, 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. <u>During the past 4 weeks</u>, 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

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

BMS Adult Codebook Form II

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

88/Refused
99/Unknown

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 <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling.

<u>Look at your Answer Key on page 2, Section 3, Option E</u>

6. How much of the time <u>during the past 4 weeks</u>:

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

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

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

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. <u>Compared to one year ago</u>, 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.

BMS Adult Codebook Form II

1	2	3	4	5	88/Refused 99/Unknown

☐ N/A: 6 or 12 month interview

9. <u>Compared to one year ago</u>, 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**	
1	2	3	4	5	88/Refused 99/Unknown

☐ 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 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 <u>two weeks</u>, 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**

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	☐	☐	☐	☐	☐	88/Refused 99/Unknown
2. Are you able to go up and down stairs at a normal pace? pfa21	☐	☐	☐	☐	☐	88/Refused 99/Unknown
3. Are you able to go for a walk of at least 15 minutes? pfa23	☐	☐	☐	☐	☐	88/Refused 99/Unknown
4. Are you able to run errands and shop? pfa53	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88/Refused 99/Unknown
6. I found it hard to focus on anything other than my anxiety edanx40	☐	☐	☐	☐	☐	88/Refused 99/Unknown
7. My worries overwhelmed me edanx41	☐	☐	☐	☐	☐	88/Refused 99/Unknown
8. I felt uneasy edanx53	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88/Refused 99/Unknown
10. I felt helpless eddep06	☐	☐	☐	☐	☐	88/Refused 99/Unknown
11. I felt depressed eddep29	☐	☐	☐	☐	☐	88/Refused 99/Unknown
12. I felt hopeless eddep41	☐	☐	☐	☐	☐	88/Refused 99/Unknown

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

BMS Adult Codebook Form II

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	☐	☐	☐	☐	☐	88/Refused 99/Unknown
14. I have trouble <u>starting</u> things because I am tired an3	☐	☐	☐	☐	☐	88/Refused 99/Unknown
In the past 7 days…						
15. How run-down did you feel on average? fatexp41	☐	☐	☐	☐	☐	88/Refused 99/Unknown
16. How fatigued were you on average? fatexp40	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	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	☐ 5	☐ 4	☐3	☐2	☐1	88/Refused 99/Unknown
19. I had a problem with my sleep sleep20	☐ 1	☐ 2	☐3	☐4	☐5	88/Refused 99/Unknown
20. I had difficulty falling asleep sleep44	☐ 1	☐ 2	☐3	☐4	☐5	88/Refused 99/Unknown

ABILITY TO PARTICIPATE IN SOCIAL ROLES AND ACTIVITIES

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

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

BMS Adult Codebook Form II

24. I have trouble doing all of the activities with friends that I want to do srpper46	☐	☐	☐	☐	☐	88/Refused 99/Unknown

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	☐	☐	☐	☐	☐	88/Refused 99/Unknown
26. How much did pain interfere with work around the home? painin22	☐	☐	☐	☐	☐	88/Refused 99/Unknown
27. How much did pain interfere with your ability to participate in social activities? painin31	☐	☐	☐	☐	☐	88/Refused 99/Unknown
28. How much did pain interfere with your household chores? painin34	☐	☐	☐	☐	☐	88/Refused 99/Unknown

Pain Intensity

	No pain										Worst imaginable pain	
In the past 7 days…	0	1	2	3	4	5	6	7	8	9	10	
29. How would you rate your pain on average? global07	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88/Refused 99/Unknown

14

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

BMS Adult Codebook Form II

2. Because of my injury, I felt left out of things. nqstg04	☐	☐	☐	☐	☐	88/Refused 99/Unknown
3. Because of my injury, people avoided looking at me. nqstg08	☐	☐	☐	☐	☐	88/Refused 99/Unknown
4. I felt embarrassed about my injury. nqstg16	☐	☐	☐	☐	☐	88/Refused 99/Unknown
5. Because of my injury, some people seemed uncomfortable with me. nqstg01	☐	☐	☐	☐	☐	88/Refused 99/Unknown
6. I felt embarrassed because of my physical limitations. nqstg17	☐	☐	☐	☐	☐	88/Refused 99/Unknown
7. Because of my injury, people were unkind to me. nqstg05	☐	☐	☐	☐	☐	88/Refused 99/Unknown
8. Some people acted as though it was my fault I have this injury. nqstg21	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
BH2. Dressing yourself? bshs_2	☐	☐	☐	☐	☐	88 / 99
BH3. Getting in and out of a chair? bshs_3	☐	☐	☐	☐	☐	88 / 99
BH4. Signing your name? bshs_4	☐	☐	☐	☐	☐	88 / 99
BH5. Eating with utensils? bshs_5	☐	☐	☐	☐	☐	88 / 99
BH6. Tying shoelaces, bows, etc? bshs_6	☐	☐	☐	☐	☐	88 / 99
BH7. Picking up coins from a flat surface? bshs_7	☐	☐	☐	☐	☐	88 / 99
BH8. Turning a doorknob? bshs_8	☐	☐	☐	☐	☐	88 / 99
BH9. Working in your old job performing your old duties? bshs_9	☐	☐	☐	☐	☐	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	

15

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. bshs_10	☐	☐	☐	☐	☐	88 / 99
BH11. I often feel sad or blue. bshs_11	☐	☐	☐	☐	☐	88 / 99
BH12. At times, I think I have an emotional problem. bshs_12	☐	☐	☐	☐	☐	88 / 99
BH13. I am not interested in doing things with my friends. bshs_13	☐	☐	☐	☐	☐	88 / 99
BH14. I do not enjoy visiting people. bshs_14	☐	☐	☐	☐	☐	88 / 99
BH15. I have no one to talk to about my problems. bshs_15	☐	☐	☐	☐	☐	88 / 99
BH16. I have feelings of being trapped or caught. bshs_16	☐	☐	☐	☐	☐	88 / 99
BH17. My injury has put me further away from my family. bshs_17	☐	☐	☐	☐	☐	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. bshs_18	☐	☐	☐	☐	☐	88 / 99
BH19. I do not like the way my family acts around me. bshs_19	☐	☐	☐	☐	☐	88 / 99
BH20. My family would be better off without me. bshs_20	☐	☐	☐	☐	☐	88 / 99
BH21. I feel frustrated because I cannot be sexually aroused as well as I used to. bshs_21	☐	☐	☐	☐	☐	88 / 99
BH22. I am simply not interested in sex anymore. bshs_22	☐	☐	☐	☐	☐	88 / 99
BH23. I no longer hug, hold, or kiss. bshs_23	☐	☐	☐	☐	☐	88 / 99
BH24. Sometimes, I would like to forget that my appearance has changed. bshs_24	☐	☐	☐	☐	☐	88 / 99
BH25. I feel that my burn is unattractive to others. bshs_25	☐	☐	☐	☐	☐	88 / 99
BH26. My general appearance really bothers me. bshs_26	☐	☐	☐	☐	☐	88 / 99
BH27. The appearance of my scars bothers me. bshs_27	☐	☐	☐	☐	☐	88 / 99
BH28. Being out in the sun bothers me. bshs_28	☐	☐	☐	☐	☐	88 / 99
BH29. Hot weather bothers me. bshs_29	☐	☐	☐	☐	☐	88 / 99
BH30. I cannot get out and do things in hot weather. bshs_30	☐	☐	☐	☐	☐	88 / 99

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

BMS Adult Codebook Form II

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

17

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

BMS Adult Codebook Form II

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 (**E**ye-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 *memories, thoughts, or images* of your burn injury? pclc_1	☐	☐	☐	☐	☐	88 / 99
2. Repeated, disturbing *dreams* of your burn injury? pclc_2	☐	☐	☐	☐	☐	88 / 99
3. Suddenly *acting or feeling* as if your burn injury *were happening* again (as if you were reliving it)? pclc_3	☐	☐	☐	☐	☐	88 / 99
4. Feeling *very upset* when *something reminded* you of your burn injury? pclc_4	☐	☐	☐	☐	☐	88 / 99
5. Having *physical reactions* (e.g., heart pounding, trouble breathing, or sweating) when *something reminded* you of your burn injury? pclc_5	☐	☐	☐	☐	☐	88 / 99
6. Avoid *thinking about* or *talking about* your burn injury or avoid *having feelings* related to it? pclc_6	☐	☐	☐	☐	☐	88 / 99
7. Avoid *activities or situations* because they *remind you* of your burn injury? pclc_7	☐	☐	☐	☐	☐	88 / 99

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

BMS Adult Codebook Form II

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

CIQ:

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

19

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

BMS Adult Codebook Form II

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

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

BMS Adult Codebook Form II

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	☐	☐	☐	☐	☐	☐	88 / 99
2. I have a greater appreciation for the value of my own life ptgi_2	☐	☐	☐	☐	☐	☐	88 / 99
3. I am able to do better things with my life. ptgi_3	☐	☐	☐	☐	☐	☐	88 / 99
4. I have a better understanding of spiritual matters. ptgi_4	☐	☐	☐	☐	☐	☐	88 / 99
5. I have a greater sense of closeness with others. ptgi_5	☐	☐	☐	☐	☐	☐	88 / 99
6. I established a new path for my life. ptgi_6	☐	☐	☐	☐	☐	☐	88 / 99
7. I know better that I can handle difficulties. ptgi_7	☐	☐	☐	☐	☐	☐	88 / 99
8. I have a stronger religious faith. ptgi_8	☐	☐	☐	☐	☐	☐	88 / 99
9. I've discovered that I'm stronger than I thought I was. ptgi_9	☐	☐	☐	☐	☐	☐	88 / 99
10. I learned a great deal about how wonderful people are. ptgi_10	☐	☐	☐	☐	☐	☐	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

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

BMS Adult Codebook Form II

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

    1. ☐ House
    2. ☐ Apartment
    3. ☐ Mobile home
    4. ☐ Institution
    5. ☐ Homeless
    6. ☐ Other

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

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. ☐ Alone livingafu___1
    2. ☐ Spouse/partner/significant other livingafu___2
    3. ☐ Friend livingafu___3
    4. ☐ Parent or step-parent livingafu___4
    5. ☐ Other relative (siblings, grandparents) livingafu___5
    6. ☐ Others, not part of family livingafu___6
    7. ☐ Guardian livingafu___7
    8. ☐ Young children livingafu___8
    9. ☐ Adult children livingafu___9

    88. ☐ Declined to answer/Refused livingafu___88
    99. ☐ Unknown livingafu___99

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

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

    1. ☐ Married; living common-law or with a partner
    2. ☐ Separated
    3. ☐ Divorced
    4. ☐ Widowed
    5. ☐ Single (not married)
    99. ☐ Unknown

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

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

"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."

    hinccatfup
    1. ☐ Less than $25,000
    2. ☐ $25,000-$49,999
    3. ☐ $50,000-$99,999
    4. ☐ $100,000-$149,999
    5. ☐ $150,000-$199,999

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

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

BMS Adult Codebook Form II

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)

(fill in # of
8. In the past year, how many months did you work at a regular job? __mrjobfup_____*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   *Instructions: skip to #10, below*
   5. ☐ Volunteer
   6. ☐ Retired
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown   66-"Not working" on old forms
Old variable was named "employfu".   77-Not applicable due to age

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**

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

BMS Adult Codebook Form II

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#13 and 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   88. ☐ Declined to answer/Refused
    2. ☐ $25,000-$40,999   99. ☐ Unknown
    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)

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)*

24

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

BMS Adult Codebook Form II

99. ☐ Unknown

Interviewer Instructions: If in school and this is a 6, 12, 0r 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. ☐ Same program full time
2. ☐ Same program part time
3. ☐ New program full time
4. ☐ New program part time
5. ☐ Did not resume school
6. ☐ Returned to individual program, home school
7. ☐ Not in school
77. Not applicable—5, 10, 15, etc, year follow-up.

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

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

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

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. ☐ 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

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

25

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

BMS Adult Codebook Form II

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   88. ☐ Declined to answer/Refused
    2. ☐ Yes   99. ☐ Unknown
    77. ☐ Not applicable (high school diploma or attended college)

19. Are you currently receiving <u>disability</u> 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)*
                                        88. ☐ Declined to answer/Refused
    2. ☐ Social Security Disability   99. ☐ Unknown
    3. ☐ Private long term insurance disability income
    4. ☐ Supplemental security income (SSI)
    5. ☐ Worker's compensation
    6. ☐ Other _____ disincfupo_____

Interviewer Instructions: If the participant is receiving disability income, continue with #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   88. ☐ Declined to answer/Refused
    2. ☐ No   99. ☐ Unknown

22. Do you currently have any psychological issues, such as depression or anxiety? pyschisfup
    1. ☐ Yes   88. ☐ Declined to answer/Refused
    2. ☐ No   99. ☐ Unknown

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

BMS Adult Codebook Form II

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. ☐ 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)
 77. ☐ Not applicable (no burn care costs)

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

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

 1. ☐ No
 2. ☐ Yes

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

25. Have you ever served in the military? milfup

 1. ☐ No
 2. ☐ Yes

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

Is there anything else you would like to tell us?_____
_____
_____
We're done with the survey. Thank you very much for your participation in this research study!"

Indicate time survey ended: _____

BMS Adult Review of Systems CodebookForm II: <u>Follow-up</u>

NewMSID_____

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

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

NewMSID_____

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

11. med11	
12. med12	

Today's Date: ___ ___ / ___ ___ / ___ ___ disdcdate
(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
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*

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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcself2, chcself2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcself3, chcself1a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcself4, chcself4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcself5, chcself5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcself6, chcself6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcself8, chcself8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
10. with Type 1 or Type 2 diabetes? chcself10, chcself10a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
11. with Growth? chcself11, chcself11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
12. Sleeping? chcself12, chcself12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
13. with Repeated infections? chcself13, chcself13a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
14. with Breathing (eg asthma)? chcself14, chcself14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
16. with other Skin problems (eg eczema)? chcself16, chcself16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
17. with the Heart (such as a birth defect)? chcself17, chcself17a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99

3

18. with Pain? chcself18, chcself18a	☐Yes=1 ☐No=0	☐ ☐ ☐ ☐ ☐ ☐ ☐

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. pa066pre	☐	☐	☐	☐	☐	88 / 99
2. My life was just right pa067pre	☐	☐	☐	☐	☐	88 / 99
3. I had a good life pa070pre	☐	☐	☐	☐	☐	88 / 99
4. I had what I wanted in life pa071pre	☐	☐	☐	☐	☐	88 / 99

CIQ 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:

4

1. Did you take responsibility for personal grooming when asked? cip2_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 you participate in the following activities outside of your home?

2: Shopping ci3_pre
    1. ☐ Never
    2. ☐ 1-4 times
    3. ☐ 5 or more times

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

3: Leisure activities such as movies, sports, and restaurants. ci4_pre
    1. ☐ Never
    2. ☐ 1-4 times
    3. ☐ 5 or more times

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

4: Visiting friends or relatives ci5_pre
    1. ☐ Never
    2. ☐ 1-4 times
    3. ☐ 5 or more times

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

During the 4 weeks before your burn:

5: When you participated in leisure activities did you usually do this alone or with others?
ci6_pre
    88. ☐ Declined to answer/Refused
    99. ☐ Unknown
    1. ☐ Mostly alone
    2. ☐ Mostly with friends who have burn injuries *(N/A for Form I)*
    3. ☐ Mostly with family members
    4. ☐ Mostly with friends who do not have burn injuries
    5. ☐ With a combination of family and friends

6: Did you have a best friend with whom you confided? ci7_pre
    1. ☐ Yes
    2. ☐ No

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

Pre-Injury Demographics

1. Before your burn injury, where were you living? (Choose only one) resdenc
    1. ☐ 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)
   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
   2. ☐ Not in school   88. ☐ Declined to answer/Refused
   3. ☐ In school/below age appropriate   99. ☐ Unknown

Interviewer instructions: Skip to #6, below, if participant was going to school before the burn injury.
5. If you were not enrolled in school at the time of your burn injury, why not? whynot
   2. ☐ Other medical problems   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 #1and #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   88. ☐ Declined to answer/Refused
    3. ☐ Hispanic   99. ☐ Unknown
    4. ☐ Pacific Islander
    5. ☐ Asian
    6. ☐ Native American
    7. ☐ Multi-Racial
    8. ☐ 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. ☐ House   88. ☐ Declined to answer/Refused
    2   ☐ Apartment   99. ☐ Unknown
    3. ☐ Mobile home
    4. ☐ Institution
    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)
    4. ☐ Parent or step-parent livhisdis ___4
    5. ☐ Other relative (siblings, grandparents) livhisdis ___5
    6. ☐ Others, not part of family livinga___6   88. ☐ Declined to answer/Refused livhisdis ___88
    7. ☐ Guardian livhisdis ___7   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? educdis
Interviewer instructions: Ask the question as open-ended, and then mark the appropriate response below.
    1. ☐ 1 year or less   88. ☐ Declined to answer/Refused
    2. ☐ 2 years   99. ☐ Unknown
    3. ☐ 3 years
    4. ☐ 4 years
    5. ☐ 5 years
    6. ☐ 6 years
    7. ☐ 7 years
    8. ☐ 8 years

9. ☐ 9 years
10. ☐ 10 years
11. ☐ 11 or 12 years; no diploma
12. ☐ High school diploma
66. ☐ Other

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

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

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_____

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
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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcprox2, chcprox2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
11. with Growth? chcprox11, chcprox11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
12. Sleeping? chcprox12, chcprox12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
13. with Repeated infections? chcprox13, chcprox13a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
14. with Breathing (eg asthma)? chcprox14, chcprox14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99

3

| 17. with the Heart (such as a birth defect)? chcprox17, chcprox17a | ☐Yes=1 ☐No=0 | ☐ ☐ ☐ ☐ ☐ ☐ ☐ | 88 / 99 |
| 18. with Pain? chcprox18, chcprox18a | ☐Yes=1 ☐No=0 | ☐ ☐ ☐ ☐ ☐ ☐ ☐ | 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

    1. ☐ Yes
    2. ☐ No

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

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

    1. ☐Yes
    2. ☐No

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

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

    1. ☐Yes
    2. ☐No

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

These questions added with new forms in December 2015.

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

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 #1and #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.

6

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

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

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   88. ☐ Declined to answer/Refused
      2. ☐ 2 years   99. ☐ Unknown
      3. ☐ 3 years
      77. ☐ Not applicable (child is too young for school)

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   88. ☐ Declined to answer/Refused
      2. ☐ $25,000-$49,999   99. ☐ Unknown
      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)
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 <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) disincdisprx

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 ____disincdisoprx_____

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

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

Interviewer instructions: If the child is under the age of 3 years, ask the question below and then you are finished with the interview. If the child is between 3 and 7 years old, continue with the General Life Satisfaction section, 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	☐	☐	☐	☐	☐
2. My child's life was just right.	☐	☐	☐	☐	☐

papxy067pre					
3. My child had a good life. papxy070pre	☐	☐	☐	☐	☐
4. My child had what he/she wanted in life. papxy071pre	☐	☐	☐	☐	☐

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

<u>Interviewer Instructions</u>: 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.

> **<u>Introduction script:</u>**
> 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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcprox2, chcprox2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
11. with Growth? chcprox11, chcprox11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
12. Sleeping? chcprox12, chcprox12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
13. with Repeated infections? chcprox13, chcprox13a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
14. with Breathing (eg asthma)? chcprox14, chcprox14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
17. with the Heart (such as a birth defect)?	☐Yes=1	☐	☐	☐	☐	☐	☐		

chcprox17, chcprox17a	☐No=0							☐	88 / 99
18. with Pain? chcprox18, chcprox18a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	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.

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?
pmedprox
    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?
imedprox
    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?
wmedprox
    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?
smedprox
    1. ☐Yes   88. ☐ Declined to answer/Refused
    2. ☐No   99. ☐ Unknown

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	☐	☐	☐	☐	☐	88 / 99
2. My child's life was just right. papxy067pre	☐	☐	☐	☐	☐	88 / 99
3. My child had a good life. papxy070pre	☐	☐	☐	☐	☐	88 / 99
4. My child had what he/she wanted in life. papxy071pre	☐	☐	☐	☐	☐	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
    0=not checked   livingaprx__88, 88. ☐ Declined to answer/Refused
    1=checked   livingaprx_99,   99. ☐ Unknown

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn injury?". Also changed variable so that multiple answers were acceptable. 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   88. ☐ Declined to answer/Refused
3. ☐ Hispanic   99. ☐ Unknown
4. ☐ Pacific Islander
5. ☐ Asian
6. ☐ Native American
7. ☐ Multi-Racial
8. ☐ Other

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

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 cor
Interviewer instructions: Ask the question as open-ende

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 <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) disincdisprx

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

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 ____disincdisoprx_____

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? cip2prx_pre

    1. ☐ Often   88. ☐ Declined to answer/Refused
    2. ☐ Sometimes   99. ☐ Unknown
    3. ☐ Never

Approximately how many times during the 4 weeks before the burn did your child participate in the following activities outside of your home?
2: Shopping ci3prx_pre

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

3: Leisure activities such as movies, sports, and restaurants. ci4prx_pre

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

4: Visiting friends or relatives ci5prx_pre

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

9

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 Option 14 added with new forms in 2015

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

BMS Pediatric 8-12 Codebook Form II
NewMSID_____

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.

BMS Pediatric 8-12 Codebook Form II
NewMSID_____

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	☐	☐	☐	☐	☐	88 / 99
2. I think people would not want to touch me. bodyim_2	☐	☐	☐	☐	☐	88 / 99
3. I feel unsure of myself among strangers. bodyim_3	☐	☐	☐	☐	☐	88 / 99
4. Changes in my appearance have interfered with my relationships. bodyim_4	☐	☐	☐	☐	☐	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 cpss_1	☐	☐	☐	☐	88 / 99
2. Having bad dreams or nightmares cpss_2	☐	☐	☐	☐	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	☐	☐	☐	☐	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	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
6. Trying not to think about, talk about, or have feelings about your burn injury cpss_6	☐	☐	☐	☐	88 / 99
7. Trying to avoid activities, people, or places that remind you of your burn injury cpss_7	☐	☐	☐	☐	88 / 99
8. Not being able to remember an important part of your burn injury cpss_8	☐	☐	☐	☐	88 / 99
9. Having much less interest or doing things you used to do cpss_9	☐	☐	☐	☐	88 / 99
10. Not feeling close to people around you cpss_10	☐	☐	☐	☐	88 / 99

3

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) cpss_11	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
13. Having trouble falling or staying asleep cpss_13	☐	☐	☐	☐	88 / 99
14. Feeling irritable or having fits of anger cpss_14	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
16. Being overly careful (for example, checking to see who is around you and what is around you) cpss_16	☐	☐	☐	☐	88 / 99
17. Being jumpy or easily startled (for example, when someone walks up behind you) cpss_17	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt upset pr714r1	☐	☐	☐	☐	☐	88 / 99
3. I felt fed up pr5045r1	☐	☐	☐	☐	☐	88 / 99
4. I was so angry I felt like throwing something pr2319ar1	☐	☐	☐	☐	☐	88 / 99
5. I was so angry I felt like yelling at somebody pr2581r1	☐	☐	☐	☐	☐	88 / 99
6. When I got mad, I stayed mad proang_6 (not administered on spanish forms)	☐	☐	☐	☐	☐	88 / 99

4

BMS Pediatric 8-12 Codebook Form II
NewMSID_____

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	☐	☐	☐	☐	☐	88 / 99
2. I could get up from the floor pr4124r1	☐	☐	☐	☐	☐	88 / 99
3. I could walk up stairs without holding on to anything pr2707r2	☐	☐	☐	☐	☐	88 / 99
4. I have been physically able to do the activities I enjoy most pr5023r1	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt nervous pr713r1	☐	☐	☐	☐	☐	88 / 99
3. I felt worried pr5044r1	☐	☐	☐	☐	☐	88 / 99
4. I worried when I was at home pr3459br1	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt lonely pr711r1	☐	☐	☐	☐	☐	88 / 99
3. I felt sad pr228r1	☐	☐	☐	☐	☐	88 / 99
4. It was hard for me to have fun pr3952ar2	☐	☐	☐	☐	☐	88 / 99

Fatigue

In the past 7 days…	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always

5

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	☐	☐	☐	☐	☐
					88 / 99
2. I got tired easily pr2876r1	☐	☐	☐	☐	☐
					88 / 99
3. I was too tired to do sports or exercise pr4241r2	☐	☐	☐	☐	☐
					88 / 99
4. I was too tired to enjoy the things I like to do pr4196r1	☐	☐	☐	☐	☐
					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	☐	☐	☐	☐	☐	88 / 99
2. I was able to count on my friends pr5058r1	☐	☐	☐	☐	☐	88 / 99
3. My friends and I helped each other out pr5055r1	☐	☐	☐	☐	☐	88 / 99
4. Other kids wanted to be my friend pr233r2	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. It was hard for me to pay attention when I had pain pr9004	☐	☐	☐	☐	☐	88 / 99
3. It was hard for me to run when I had pain pr2045r1	☐	☐	☐	☐	☐	88 / 99
4. It was hard for me to walk one block when I had pain pr2049r1	☐	☐	☐	☐	☐	88 / 99

Pain Intensity

In the past 7 days…
How bad was your pain on average? pr9033r1

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

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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

6

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	☐	☐	☐	☐	☐	88 / 99
2. My life is just right pa067	☐	☐	☐	☐	☐	88 / 99
3. I have a good life pa070	☐	☐	☐	☐	☐	88 / 99
4. I have what I want in life pa071	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt angry when I was itching bmsitch_2	☐	☐	☐	☐	☐	88 / 99
3. I had trouble doing schoolwork when I was itching bmsitch_3	☐	☐	☐	☐	☐	88 / 99
4. It was hard for me to pay attention when I was itching bmsitch_4	☐	☐	☐	☐	☐	88 / 99
5. It was hard for me to have fun when I was itching bmsitch_5	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88/Refused
2. I can now handle big problems better than I used to. ptgic_2	☐	☐	☐	☐	☐	88/Refused
3. I know what is important to me better than I used to. ptgic_3	☐	☐	☐	☐	☐	88/Refused
4. I understand how God works better than I used to. ptgic_4	☐	☐	☐	☐	☐	88/Refused
5. I feel closer to other people (friends or family) than I used to. ptgic_5	☐	☐	☐	☐	☐	88/Refused
6. I appreciate (enjoy) each day more than I used to. ptgic_6	☐	☐	☐	☐	☐	88/Refused

BMS Pediatric 8-12 Codebook Form II
NewMSID_____

7. I now have a chance to do some things I couldn't do before. ptgic_7	☐	☐	☐	☐	☐	88/Refused
8. My faith (belief) in God is stronger than it was before. ptgic_8	☐	☐	☐	☐	☐	88/Refused
9. I have learned that I can deal with more things than I thought I could before. ptgic_9	☐	☐	☐	☐	☐	88/Refused
10. I have new ideas about how I want things to be when I grow up. ptgic_10	☐	☐	☐	☐	☐	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 ⟶   *Interviewer Instructions: Update date*
   3. ☐ Death due to non-burn related complications ⟶   *and cause of death on Patient Status*
   4. ☐ Unable to locate   *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

1

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
       0=not checked
       1=checked

88. ☐ Declined to answer/Refused
services___88
99. ☐ Unknown services___99

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*)
   numsurg (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)   88. ☐ Declined to answer/Refused
   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 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
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*

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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcself2, chcself2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcself3, chcself1a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcself4, chcself4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcself5, chcself5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcself6, chcself6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcself8, chcself8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
10. with Type 1 or Type 2 diabetes? chcself10, chcself10a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
11. with Growth? chcself11, chcself11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
12. Sleeping? chcself12, chcself12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
13. with Repeated infections? chcself13,	☐Yes=1	☐	☐	☐	☐	☐	☐		

chcself13a	☐No=0							☐	88 / 99
14. with Breathing (eg asthma)? chcself14, chcself14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
16. with other Skin problems (eg eczema)? chcself16, chcself16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
17. with the Heart (such as a birth defect)? chcself17, chcself17a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
18. with Pain? chcself18, chcself18a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	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   88. ☐ Declined to answer/Refused
   2. ☐No   99. ☐ Unknown

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

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

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

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	☐	☐	☐	☐	☐	88 / 99
2. I think people would not want to touch me. bodyim_2	☐	☐	☐	☐	☐	88 / 99
3. I feel unsure of myself among strangers. bodyim_3	☐	☐	☐	☐	☐	88 / 99
4. Changes in my appearance have interfered with my relationships.	☐	☐	☐	☐	☐	88 / 99

7

bodyim_4					

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	☐	☐	☐	☐	88 / 99
2. Having bad dreams or nightmares cpss_2	☐	☐	☐	☐	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	☐	☐	☐	☐	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	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
6. Trying not to think about, talk about, or have feelings about your burn injury cpss_6	☐	☐	☐	☐	88 / 99
7. Trying to avoid activities, people, or places that remind you of your burn injury cpss_7	☐	☐	☐	☐	88 / 99
8. Not being able to remember an important part of your burn injury cpss_8	☐	☐	☐	☐	88 / 99
9. Having much less interest or doing things you used to do cpss_9	☐	☐	☐	☐	88 / 99
10. Not feeling close to people around you cpss_10	☐	☐	☐	☐	88 / 99
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) cpss_11	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
13. Having trouble falling or staying asleep cpss_13	☐	☐	☐	☐	88 / 99
14. Feeling irritable or having fits of anger cpss_14	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
16. Being overly careful (for example, checking to see who is	☐	☐	☐		88 / 99

8

around you and what is around you) cpss_16				☐	
17. Being jumpy or easily startled (for example, when someone walks up behind you) cpss_17	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt upset pr714r1	☐	☐	☐	☐	☐	88 / 99
3. I felt fed up pr5045r1	☐	☐	☐	☐	☐	88 / 99
4. I was so angry I felt like throwing something pr2319ar1	☐	☐	☐	☐	☐	88 / 99
5. I was so angry I felt like yelling at somebody pr2581r1	☐	☐	☐	☐	☐	88 / 99
6. When I got mad, I stayed mad proang_6 (not administered on spanish forms)	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I could get up from the floor pr4124r1	☐	☐	☐	☐	☐	88 / 99
3. I could walk up stairs without holding on to anything pr2707r2	☐	☐	☐	☐	☐	88 / 99
4. I have been physically able to do the activities I enjoy most pr5023r1	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt nervous pr713r1	☐	☐	☐	☐	☐	88 / 99
3. I felt worried pr5044r1	☐	☐	☐	☐	☐	88 / 99

4. I worried when I was at home pr3459br1	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt lonely pr711r1	☐	☐	☐	☐	☐	88 / 99
3. I felt sad pr228r1	☐	☐	☐	☐	☐	88 / 99
4. It was hard for me to have fun pr3952ar2	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I got tired easily pr2876r1	☐	☐	☐	☐	☐	88 / 99
3. I was too tired to do sports or exercise pr4241r2	☐	☐	☐	☐	☐	88 / 99
4. I was too tired to enjoy the things I like to do pr4196r1	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I was able to count on my friends pr5058r1	☐	☐	☐	☐	☐	88 / 99
3. My friends and I helped each other out pr5055r1	☐	☐	☐	☐	☐	88 / 99
4. Other kids wanted to be my friend pr233r2	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99

10

2. It was hard for me to pay attention when I had pain pr9004	☐	☐	☐	☐	☐	88 / 99
3. It was hard for me to run when I had pain pr2045r1	☐	☐	☐	☐	☐	88 / 99
4. It was hard for me to walk one block when I had pain pr2049r1	☐	☐	☐	☐	☐	88 / 99

Pain Intensity

In the past 7 days…
How bad was your pain on average? pr9033r1

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

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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	☐	☐	☐	☐	☐	88 / 99
2. My life is just right	☐	☐	☐	☐	☐	88 / 99
3. I have a good life	☐	☐	☐	☐	☐	88 / 99
4. I have what I want in life	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. I felt angry when I was itching bmsitch_2	☐	☐	☐	☐	☐	88 / 99
3. I had trouble doing schoolwork when I was itching bmsitch_3	☐	☐	☐	☐	☐	88 / 99
4. It was hard for me to pay attention when I was itching bmsitch_4	☐	☐	☐	☐	☐	88 / 99
5. It was hard for me to have fun when I was itching bmsitch_5	☐	☐	☐	☐	☐	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

11

					know	
1. I learned how nice and helpful some people can be. ptgic_1	☐	☐	☐	☐	☐	88/Refused
2. I can now handle big problems better than I used to. ptgic_2	☐	☐	☐	☐	☐	88/Refused
3. I know what is important to me better than I used to. ptgic_3	☐	☐	☐	☐	☐	88/Refused
4. I understand how God works better than I used to. ptgic_4	☐	☐	☐	☐	☐	88/Refused
5. I feel closer to other people (friends or family) than I used to. ptgic_5	☐	☐	☐	☐	☐	88/Refused
6. I appreciate (enjoy) each day more than I used to. ptgic_6	☐	☐	☐	☐	☐	88/Refused
7. I now have a chance to do some things I couldn't do before. ptgic_7	☐	☐	☐	☐	☐	88/Refused
8. My faith (belief) in God is stronger than it was before. ptgic_8	☐	☐	☐	☐	☐	88/Refused
9. I have learned that I can deal with more things than I thought I could before. ptgic_9	☐	☐	☐	☐	☐	88/Refused
10. I have new ideas about how I want things to be when I grow up. ptgic_10	☐	☐	☐	☐	☐	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. ☐ House
   2. ☐ Apartment
   3. ☐ Mobile home
   4. ☐ Institution
   5. ☐ Homeless

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

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.

        88. ☐ Declined to answer/Refused
4. ☐ Parent or step-parent livingafu___4   livingafu___88
5. ☐ Other relative (siblings, grandparents) livingafu___   99. ☐ Unknown
6. ☐ Others, not part of family livingafu___6   livingafu___99
7. ☐ Guardian livingafu___7

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, 0r 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. ☐ 1 year or less
2. ☐ 2 years
3. ☐ 3 years
4. ☐ 4 years
5. ☐ 5 years
6. ☐ 6 years
7. ☐ 7 years
8. ☐ 8 years
9. ☐ 9 years
10. ☐ 10 years
11. ☐ 11 or 12 years; no diploma
12. ☐ High school diploma
66. ☐ Other

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

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

1. ☐ I am not receiving disability income (*Interviewer Instructions: skip to #13, below, 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 #12

12. If yes, are you receiving disability income due to your burn injury? disincbrn
1. ☐ Yes, I am receiving disability income due to my burn injury
2. ☐ No, I am not receiving disability income due to my burn injury
77. ☐ Not applicable (not receiving disability income)
99. ☐ Unknown

13. Do you currently have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? physprobfup
1. ☐ Yes   2. ☐ No

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

14. Do you currently have any psychological issues, such as depression or anxiety? psychisfup
1. ☐ Yes   2. ☐ No   88. ☐ Declined to answer/Refused
99. ☐ Unknown

14

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: _____

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

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

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

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.*

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

- *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   88. ☐ Declined to answer/Refused servicesprx___88

    3. ☐ Physical therapy servicesprx___3

    4. ☐ Speech language pathology servicesprx___4   99. ☐ Unknown servicesprx___99

    5. ☐ Social work servicesprx___5

    6. ☐ Psychological services servicesprx___6

    7. ☐ Vocational services servicesprx___7

    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…

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

BMS Pediatric Proxy 0-7 Codebook Form II

NewMSID_____

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?
    1. ☐ Yes
    2. ☐ No
    77. ☐ Not applicable (no OT/PT received)

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

6. Other facility? ther_otrprx
    1. ☐ Yes
    2. ☐ No
    77. ☐ Not applicable (no OT/PT received)

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

7. Since your last interview [*provide date*], has your child had any burn related surgeries? surgery_fuprx

88. ☐ Declined to answer/Refused

    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*]?
    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

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

13. Which burn related surgeries has your child had since your last interview?
(Choose all that apply)

88. ☐ Declined to answer/Refused

1. ☐ Surgery for open wounds surgtypeprx___1   surgtypeprx___88
2. ☐ Surgery for joint contractures surgtypeprx___2   99. ☐ Unknown surgtypeprx___99
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

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 amput1prx ___7; 0=not checked; 1=checked
8. ☐ Yes, digits only right numudgtrfuprx ___(fill in # of digits) (Thumb amputated? thumbrfuprx ☐
   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

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

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

88. ☐ Declined to answer/Refused amputfu2prx___88

99. ☐ Unknown amputfu2prx___99

Notes:
New variable added with new Forms in 2015

Child Health Conditions

Interviewer instructions: Each question below is answered "yes" or "no".
If answered "yes", then ask "To what extent does this problem affect your 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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcprox2, chcprox2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
10. with Type 1 or Type 2 diabetes?	☐Yes=1	☐	☐	☐	☐	☐	☐	☐	88 / 99

6

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

BMS Pediatric Proxy 0-7 Codebook Form II

NewMSID_____

chcprox10, chcprox10a	☐No=0							
11. with Growth? chcprox11, chcprox11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
12. Sleeping? chcprox12, chcprox12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
13. with Repeated infections? chcprox13, chcprox13a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
14. with Breathing (eg asthma)? chcprox14, chcprox14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
17. with the Heart (such as a birth defect)? chcprox17, chcprox17a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
18. with Pain? chcprox18, chcprox18a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 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	☐	☐	☐	☐	☐
2. Itching bmsitch	☐	☐	☐	☐	☐

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

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

4. In the past 12 months, did your child take medication for being sad, empty, or depressed?
smedprx
1. ☐ Yes   88. ☐ Declined to answer/Refused
2. ☐ No   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   88. ☐ Declined to answer/Refused
2. ☐ Apartment   99. ☐ Unknown
3. ☐ Mobile home
4. ☐ Institution
5. ☐ Homeless
6. ☐ Other

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   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 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, 0r 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   88. ☐ Declined to answer/Refused
2. ☐ Same program part time   99. ☐ Unknown

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

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?"). educfupprx
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 <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) disincfupprx

1. ☐ My child is not receiving disability income (*Interviewer Instructions: skip to #13, on the next page, if the child is not receiving disability income)*
2. ☐ Social Security Disability
4. ☐ Supplemental security income (SSI)

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

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

6. ☐ Other _____disincfupoprx_____

Interviewer Instructions: If the child is receiving disability income, continue with #12

12. If yes, is your child receiving disability income due to his/her burn injury? disincbrnprx
   1. ☐ Yes, my child is receiving disability income due to his/her burn injury
   2. ☐ No, my child is not receiving disability income due to his/her burn injury
   77. ☐ Not applicable (not receiving disability income)
   99. ☐ Unknown

13. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? physprobfupprx
   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   88. ☐ Declined to answer/Refused
   2. ☐ $25,000-$49,999   99. ☐ Unknown
   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)
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)   88. ☐ Declined to answer/Refused
   3. ☐ Private insurance   99. ☐ Unknown
   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)

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

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	☐	☐	☐	☐	☐	88 / 99
2. This child thinks that people would not want to touch him/her. bodyimp_2	☐	☐	☐	☐	☐	88 / 99
3. This child feels unsure of himself/herself among strangers. bodyimp_3	☐	☐	☐	☐	☐	88 / 99
4. Changes in this child's appearance have interfered with his/her relationships. bodyimp_4	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	88 / 99
3. Sits on floor without support of pillow or couch pedi_3	☐	☐	☐	☐	88 / 99
4. Walks while holding onto furniture or walls pedi_4	☐	☐	☐	☐	88 / 99
6. Walks outdoors on grass, mulch or gravel pedi_6	☐	☐	☐	☐	88 / 99

11

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

BMS Pediatric Proxy 0-7 Codebook Form II

NewMSID_____

7. When running, is able to go around people and objects pedi_7	☐	☐	☐	☐	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	☐	☐	☐	88 / 99
2. Argues a lot with adults. pedproxang02	☐	☐	☐	88 / 99
3. Is easily annoyed by others pedproxang06	☐	☐	☐	88 / 99
4. Gets back at people pedproxang08	☐	☐	☐	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	☐	☐	☐	88 / 99
2. Cries a lot. pedproxdep05	☐	☐	☐	88 / 99
3. Seems lonely. pedproxdep06	☐	☐	☐	88 / 99
4. Withdraws from peer activities. pedproxdep13	☐	☐	☐	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.	☐	☐	☐	☐	☐	88 / 99

12

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

BMS Pediatric Proxy 0-7 Codebook Form II
NewMSID_____

papxy066						
2. My child's life is just right. papxy067	☐	☐	☐	☐	☐	88 / 99
3. My child has a good life. papxy070	☐	☐	☐	☐	☐	88 / 99
4. My child has what he/she wants in life. papxy071	☐	☐	☐	☐	☐	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	☐	☐	☐	☐	☐	88 / 99
2. My child was enthusiastic. papxy019_3to7	☐	☐	☐	☐	☐	88 / 99
3. My child was interested. papxy021_3to7	☐	☐	☐	☐	☐	88 / 99
4. My child was confident. papxy022_3to7	☐	☐	☐	☐	☐	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
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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcprox2, chcprox2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
11. with Growth? chcprox11, chcprox11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
12. Sleeping? chcprox12, chcprox12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
13. with Repeated infections? chcprox13, chcprox13a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
14. with Breathing (eg asthma)? chcprox14, chcprox14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
17. with the Heart (such as a birth defect)?	☐Yes=1	☐	☐	☐	☐	☐	☐		

3

chcprox17, chcprox17a	☐No=0								☐	88 / 99
18. with Pain? chcprox18, chcprox18a	☐Yes=1 ☐No=0		☐	☐	☐	☐	☐	☐	☐	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.

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?
pmedprox
   1. ☐Yes
   2. ☐No

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

2. In the past month did your child take prescription medication for itch on a regular basis?
imedprox
   1. ☐Yes
   2. ☐No

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

3. In the past 12 months, did your child take medication for being, worried, tense, or anxious?
wmedprox
   1. ☐Yes
   2. ☐No

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

4. In the past 12 months, did your child take medication for being sad, empty, or depressed?
smedprox
   1. ☐Yes
   2. ☐No

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

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	☐	☐	☐	☐	☐	88 / 99
2. My child's life was just right. papxy067pre	☐	☐	☐	☐	☐	88 / 99
3. My child had a good life. papxy070pre	☐	☐	☐	☐	☐	88 / 99
4. My child had what he/she wanted in life. papxy071pre	☐	☐	☐	☐	☐	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
   0=not checked
   1=checked

   livingaprx__88, 88. ☐ Declined to answer/Refused
   livingaprx_99, 99. ☐ Unknown

The previous variable "living" was changed with the move to the new forms in 2015 to include options only for adults. Clarification was also added to "other relative" option to include "siblings, grandparents", "other", to include "not part of family". At this time, wording was changed from "living with at time of burn" to "who were you living with before your burn injury?". Also changed variable so that multiple answers were acceptable. 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 #1and #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   88. ☐ Declined to answer/Refused
    3. ☐ Hispanic   99. ☐ Unknown
    4. ☐ Pacific Islander
    5. ☐ Asian
    6. ☐ Native American
    7. ☐ Multi-Racial
    8. ☐ Other

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

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 cor 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 <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) disincdisprx

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

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 ____disincdisoprx_____

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? cip2prx_pre
      1. ☐ Often   88. ☐ Declined to answer/Refused
      2. ☐ Sometimes   99. ☐ Unknown
      3. ☐ Never

Approximately how many times during the 4 weeks before the burn did your child participate in the following activities outside of your home?
2: Shopping ci3prx_pre
      1. ☐ Never   88. ☐ Declined to answer/Refused
      2. ☐ 1-4 times   99. ☐ Unknown
      3. ☐ 5 or more times

3: Leisure activities such as movies, sports, and restaurants. ci4prx_pre
      1. ☐ Never
      2. ☐ 1-4 times   88. ☐ Declined to answer/Refused
      3. ☐ 5 or more times   99. ☐ Unknown

4: Visiting friends or relatives ci5prx_pre
        88. ☐ Declined to answer/Refused
        99. ☐ Unknown

9

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: _____

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

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

1

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

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.*

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

- *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 servicesprx___88
99. ☐ Unknown servicesprx___99

  0=not checked
  1=checked
Added in 2015

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

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

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?
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable (no OT/PT received)

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

6. Other facility? ther_otrprx
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable (no OT/PT received)

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

7. Since your last interview [*provide date*], has your child had any burn related surgeries?
surgery_fuprx
88. ☐ Declined to answer/Refused
   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*]?
   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

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

src_numsurgprx

13. Which burn related surgeries has your child had since your last interview?
(Choose all that apply)   88. ☐ Declined to answer/Refused
   1. ☐ Surgery for open wounds surgtypeprx___1   surgtypeprx___88
   2. ☐ Surgery for joint contractures surgtypeprx___2   99. ☐ Unknown surgtypeprx___99
   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
   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 amput1prx ___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: 88. ☐ Declined to answer/Refused-- amputfu1prx ___88
   New variable added with new Forms in 2015   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

5

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

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

88. ☐ Declined to answer/Refused amputfu2prx___88

99. ☐ Unknown amputfu2prx___99

Notes:
New variable added with new Forms in 2015

Child Health Conditions

Interviewer instructions: Each question below is answered "yes" or "no".
If answered "yes", then ask "To what extent does this problem affect your 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	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
2. Hearing? chcprox2, chcprox2a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
3. Learning and understanding? chcprox3, chcprox3a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
5. Controlling emotions or behavior? chcprox5, chcprox5a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
6. with Seizures or epilepsy? chcprox6, chcprox6a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
8. with Teeth and gums? chcprox8, chcprox8a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99
9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐	88 / 99

6

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
11. with Growth? chcprox11, chcprox11a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
12. Sleeping? chcprox12, chcprox12a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
13. with Repeated infections? chcprox13, chcprox13a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
14. with Breathing (eg asthma)? chcprox14, chcprox14a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
16. with other Skin problems (eg eczema)? chcprox16, chcprox16a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
17. with the Heart (such as a birth defect)? chcprox17, chcprox17a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 88 / 99
18. with Pain? chcprox18, chcprox18a	☐Yes=1 ☐No=0	☐	☐	☐	☐	☐	☐	☐ 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 Medication

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

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

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

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

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

PROMIS-Anger

In the past 7 days…	0= Never	1= Almost Never	2= Some-times	3= Often	4= Almost always	
1. My child felt mad pf1anger1	☐	☐	☐	☐	☐	88 / 99
2. My child was so angry he/she felt like yelling at somebody pf1anger5	☐	☐	☐	☐	☐	88 / 99
3. My child was so angry he/she felt like throwing something pf1anger3	☐	☐	☐	☐	☐	88 / 99
4. My child felt upset pf1anger10	☐	☐	☐	☐	☐	88 / 99
5. When my child got mad, he/she stayed mad pf1anger8	☐	☐	☐	☐	☐	88 / 99

PROMIS-Depressive Symptoms

In the past 7 days…	0= Never	1= Almost Never	2= Some-times	3= Often	4= Almost always	
1. My child could not stop feeling sad pf2depr7	☐	☐	☐	☐	☐	88 / 99
2. My child felt everything in his/her life went wrong pf1depr7	☐	☐	☐	☐	☐	88 / 99
3. My child felt like he/she couldn't do anything right pf1depr5	☐	☐	☐	☐	☐	88 / 99
4. My child felt lonely pf2depr10	☐	☐	☐	☐	☐	88 / 99
5. My child felt sad pf2depr3	☐	☐	☐	☐	☐	88 / 99
6. My child thought that his/her life was bad pf2depr5	☐	☐	☐	☐	☐	88 / 99

PROMIS-Pain Interference

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

In the past 7 days…	0=Never	1=Almost Never	2=Some-times	3=Often	4=Almost always	
1. My child had trouble sleeping when he/she had pain pf2pain5	☐	☐	☐	☐	☐	88 / 99
2. My child felt angry when he/she had pain pf3pain7	☐	☐	☐	☐	☐	88 / 99
3. My child had trouble doing schoolwork when he/she had pain pf2pain2	☐	☐	☐	☐	☐	88 / 99
4. It was hard for my child to pay attention when he/she had pain pf3pain2	☐	☐	☐	☐	☐	88 / 99
5. It was hard for my child to run when he/she had pain pf2pain4	☐	☐	☐	☐	☐	88 / 99
6. It was hard for my child to walk one block when he/she had pain pf1pain4	☐	☐	☐	☐	☐	88 / 99
7. It was hard for my child to have fun when he/she had pain pf3pain4	☐	☐	☐	☐	☐	88 / 99
8. It was hard for my child to stand when he/she had pain pf4pain6	☐	☐	☐	☐	☐	88 / 99

PROMIS-Peer Relationships

In the past 7 days…	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. My child felt accepted by other kids his/her age pf3socabil9	☐	☐	☐	☐	☐	88 / 99
2. My child was able to count on his/her friends pf4socabil12	☐	☐	☐	☐	☐	88 / 99
3. My child was good at making friends pf3socabil4	☐	☐	☐	☐	☐	88 / 99
4. My child and his/her friends helped each other out pf2socrole4	☐	☐	☐	☐	☐	88 / 99
5. Other kids wanted to be my child's friend pf1socabil2	☐	☐	☐	☐	☐	88 / 99
6. Other kids wanted to be with my child pf3socrole4	☐	☐	☐	☐	☐	88 / 99
7. Other kids wanted to talk to my child pf2socabil9	☐	☐	☐	☐	☐	88 / 99

PROMIS-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. My child could do sports and exercise that other kids his/her age could do pf1mobil3	☐	☐	☐	☐	☐	88 / 99

9

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

2. My child could get up from the floor pf3mobil9	☐	☐	☐	☐	☐	88 / 99
3. My child could keep up when he/she played with other kids pf4mobil4	☐	☐	☐	☐	☐	88 / 99
4. My child could move his/her legs pf3mobil8	☐	☐	☐	☐	☐	88 / 99
5. My child could stand up without help pf3mobil3	☐	☐	☐	☐	☐	88 / 99
6. My child could stand up on his/her tiptoes pf2mobil7	☐	☐	☐	☐	☐	88 / 99
7. My child could walk up stairs without holding on to anything pf2mobil4	☐	☐	☐	☐	☐	88 / 99
8. My child has been physically able to do the activities he/she enjoys most pf1mobil1	☐	☐	☐	☐	☐	88 / 99

PROMIS-Physical function Upper Extremity

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. My child could button his/her shirt or pants pf2uprext3	☐	☐	☐	☐	☐	88 / 99
2. My child could open a jar by himself/herself pf4uprext1	☐	☐	☐	☐	☐	88 / 99
3. My child could open the rings in school binders pf3uprext11	☐	☐	☐	☐	☐	88 / 99
4. My child could pour a drink from a full pitcher pf4uprext10	☐	☐	☐	☐	☐	88 / 99
5. My child could pull a shirt on over his/her head without help pf3uprext4	☐	☐	☐	☐	☐	88 / 99
6. My child could pull open heavy doors pf3uprext9	☐	☐	☐	☐	☐	88 / 99
7. My child could put on his/her shoes without help pf2uprext2	☐	☐	☐	☐	☐	88 / 99
8. My child could use a key to unlock a door pf3uprext7	☐	☐	☐	☐	☐	88 / 99

NIH Toolbox General Life Satisfaction

Indicate how much you agree or disagree:	1= Strongly disagree	2= Disagree	3= Neither agree nor disagree	4= Agree	5= Strongly agree	
1. My child's life is going well. papxy066	☐	☐	☐	☐	☐	88 / 99
2. My child's life is just right. papxy067	☐	☐	☐	☐	☐	88 / 99
3. My child has a good life. papxy070	☐	☐	☐	☐	☐	88 / 99
4. My child has what he/she wants in	☐	☐	☐	☐	☐	88 / 99

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

life. papxy071					

BMS-Itch *(modified for BMS based on the PROMIS Pain interference)*

In the past 7 days…	0= Never	1= Almost Never	2= Some-times	3= Often	4=Almost always	
1. My child had trouble sleeping when he/she was itching bmsitchp_1	☐	☐	☐	☐	☐	88 / 99
2. My child felt angry when he/she was itching bmsitchp_2	☐	☐	☐	☐	☐	88 / 99
3. My child had trouble doing schoolwork when he/she was itching bmsitchp_3	☐	☐	☐	☐	☐	88 / 99
4. It was hard for my child to pay attention when he/she was itching bmsitchp_4	☐	☐	☐	☐	☐	88 / 99
5. It was hard for my child to have fun when he/she was itching bmsitchp_5	☐	☐	☐	☐	☐	88 / 99

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   88. ☐ Declined to answer/Refused
    3. ☐ Mobile home   99. ☐ Unknown
    4. ☐ Institution
    5. ☐ Homeless
    6. ☐ Other

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.
                                                      88. ☐ Declined to answer/Refused
    4. ☐ Parent or step-parent livingafu___4   livingafu___88
    5. ☐ Other relative (siblings, grandparents) livingafu___5   99. ☐ Unknown
                                                      livingafu___99

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

6. ☐ Others, not part of family livingafu___6
7. ☐ Guardian livingafu___7
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, 0r 24 month follow-up, ask…
7. …is it the same program or a new program as compared with your last interview? *(Or,* as compared with before his/her burn injury*, if this is a 6 month follow-up).* aprogfuprx
Interviewer Instructions: Ask as open ended question and probe about part or full time school status.
    1. ☐ Same program full time
    2. ☐ Same program part time
    3. ☐ New program full time
    4. ☐ New program part time
    5. ☐ Did not resume school
    6. ☐ Returned to individual program, home school
    7. ☐ Not in school

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

Interviewer Instructions: Skip 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?"). educfupprx

12

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

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

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

11. Is your child currently receiving <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) disincfupprx

1. ☐ My child is not receiving disability income (*Interviewer Instructions: skip to #13, on the next page, if the child is not receiving disability income*)
2. ☐ Social Security Disability
4. ☐ Supplemental security income (SSI)
6. ☐ Other _____disincfupoprx_____

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

Interviewer Instructions: If the child is receiving disability income, continue with #12

12. If yes, is your child receiving disability income due to his/her burn injury? disincbrnprx
1. ☐ Yes, my child is receiving disability income due to his/her burn injury
2. ☐ No, my child is not receiving disability income due to his/her burn injury
77. ☐ Not applicable (not receiving disability income)
99. ☐ Unknown

13. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? physprobfupprx
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)? _____ hincnumfupprx
(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." hinccatfupprx

1. ☐ Less than $25,000
2. ☐ $25,000-$49,999
3. ☐ $50,000-$99,999

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

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

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)

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)   88. ☐ Declined to answer/Refused
3. ☐ Private insurance   99. ☐ Unknown
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)
77. ☐ Not applicable (no burn care costs)

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

CIQ:
Currently:
1: Does your child take personal responsibility for grooming when asked? cip2prx

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

BMS Pediatric Proxy 8-17 Codebook Form II
NewMSID_____

1. ☐ Often
2. ☐ Sometimes
3. ☐ Never

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

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

2: Shopping ci3prx
    1. ☐ Never
    2. ☐ 1-4 times
    3. ☐ 5 or more times

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

3: Leisure activities such as movies, sports, and restaurants. ci4prx
    1. ☐ Never
    2. ☐ 1-4 times
    3. ☐ 5 or more times

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

4: Visiting friends or relatives ci5prx
    1. ☐ Never
    2. ☐ 1-4 times
    3. ☐ 5 or more times

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

5: When your child participates in leisure activities does he/she usually do this alone or with others? ci6prx
    1. ☐ Mostly alone
    2. ☐ Mostly with friends who have burn injuries
    3. ☐ Mostly with family members
    4. ☐ Mostly with friends who do not have burn injuries
    5. ☐ With a combination of family and friends

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

6: Do your child have a best friend with whom he/she can confide? ci7prx
    1. ☐ Yes
    2. ☐ No

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: _____