Burn Model System Survey Codebooks

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

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

Numbers for response categories correspond to codes unless otherwise noted.

These Codebooks include:

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

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

NewMSID (concatenation of site and MSID): _____________newmsid

MSID: __________________msid

Site (BMS center where care was received): site
1. □ Dallas—UTSW
3. □ Seattle—UW
5. □ Galveston—UTMB
6. □ Boston BMS

PS1. Primary admission criteria to Burn Model System: criteria
1. □ 10%+ TBSA 65+ yrs. w/ wound closure surgery
2. □ 20%+ TBSA 19-64 yrs. w/ wound closure surgery
3. □ 20%+ TBSA 0-18 yrs. w/ wound closure surgery
4. □ Elec. high volt./lightning w/ wound closure surgery
5. □ Hand, face, feet burn w/ wound closure surgery
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)
4. □ Eligible but unable to consent (severe cognitive impairment* due to dementia, TBI, etc) (do not collect DOB, skip to PS5)
5. □ Eligible but unable to consent (language barrier**) (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 ________________ (yyy) (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 ________________ (yyy) (code 9999 for unknown)

PS8. Gender: gender
1. □ Male
2. □ Female
PS9. Race and/or ethnicity? *(Interviewer Instructions: This item is administered as self-report in Form I, question #1 on page 20. If the participant consents, fill in this question using their self-report to the same question in Form 1. If the participant does not consent, fill in this question at the time of non-consent. If it is appropriate to ask based on interactions with the participant, gather the item by self-report by saying, “I’d like to ask you a question if that is okay. What is your race and/or ethnicity?” If it is not appropriate, gather the information by medical record.)*

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

Previous variable was ethnicity

a. Racial group? race

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

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 alive at discharge and consented to participate in the BMS research study.*

PS10. Date of admission to Model System: enc_date ________________ (yyyy/mm/dd)

(code 1900/09/09 for unknown)

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

(code 1900/08/08 for not applicable)

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

   disch_date ________________ (yyyy/mm/dd) (code 1900/09/09 for unknown)
PS13. Date of 2nd discharge from acute burn care (does not include inpatient rehab)

\[ \text{disch\_date\_2nd} \quad \text{__________________} \quad \text{(yyyy/mm/dd)} \quad \text{(code 1900/08/08 for not applicable)} \]

PS14. Date consent form signed by participant

\[ \text{__cnsnt\_date} \quad \text{_______________________} \quad \text{(yyyy/mm/dd)} \quad \text{(code 1900/09/09 for unknown)} \]

**Update follow-up information here:**

PS15. First date of return to work/school since injury: \[ \text{retrndat} \quad \text{______________} \quad \text{(yyyy/mm/dd)} \]

**Coding:**
- 1900/07/07 = not yet determined
- 1900/08/08 = not applicable
- 1900/09/09 = unknown

PS16. Date of death: \[ \text{dth\_date} \quad \text{__________________} \quad \text{(yyyy/mm/dd)} \]

**Coding:**
- 1900/07/07 = not yet determined
- 1900/08/08 = not applicable
- 1900/09/09 = unknown

PS17. Primary Cause of Death ICD-9 Code: \[ \text{deathcause1} \quad \text{__________} \quad \text{.____} \]

**Coding:**
- 77777 - Expired: Cause Unknown;
- 88888 - Not Applicable (Person Alive);
- 99999 - Unknown

PS18. Secondary Cause of Death ICD-9 Code: \[ \text{deathcause2} \quad \text{__________} \quad \text{.____} \]

**Coding:**
- 77777 - Expired: Cause Unknown;
- 88888 - Not Applicable (Person Alive);
- 99999 - Unknown

PS19. Cause of Death E-Code (External Code): \[ \text{deathcausee} \quad \text{__________} \quad \text{.____} \]

**Coding:**
- 77777 - Expired: Cause Unknown;
- 88888 - Not Applicable (Person Alive);
- 99999 - Unknown
BMS Form I Medical Record Abstraction Codebook

NewMSID__________

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

NewMSID ________________________________

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

MR1. Main cause of burn injury: pretiol
  1. ☐ Fire/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
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

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

Text field, othrehabnote, added to REDCap in March 2018, including information from Boston IRF project. This text field captures more information about category 8, other rehab facility.
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
Variable names and information are indicated in red

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)
   2. ☐ Left   4. ☐ None

MR14. Forearm (includes wrist) farmbrn (variable name prior to 1/15, with arm data, was armbRN)
   2. ☐ Left   4. ☐ None

MR15. Hand handbrn
   2. ☐ Left   4. ☐ None

MR16. Leg legbrn
   2. ☐ Left   4. ☐ None

MR17. Foot footbrn
   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)
   2. ☐ Left   4. ☐ None

MR22. Forearm (includes wrist) farmgrft (variable name prior to 10/13, with arm data, was armgrft)
   2. ☐ Left   4. ☐ None
Variable names and information are indicated in red

**BMS Form I Medical Record Abstraction Codebook**

NewMSID_________

**MR23.** Hand **handgrft**
2. □ Left 4. □ None

**MR24.** Leg **leggrft**
2. □ Left 4. □ None

**MR25.** Foot **footgrft**
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
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? thummb □
   1-Yes □ 2-No, 99-Unknown) amput1___9; 0=not checked; 1=checked
10. □ No amput1___10; 0=not checked; 1=checked
11. □ Unknown amput1___99; 0=not checked; 1=checked

Notes:
New variable added with new Forms in 2015

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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
14. □ 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
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
Medication Data Collection Table
New variable added with new Forms in December 2015

<table>
<thead>
<tr>
<th>Name of Medication Prescribed at Discharge (add as many rows as necessary) (text field for name of medication)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. meddis1</td>
</tr>
<tr>
<td>2. meddis2</td>
</tr>
<tr>
<td>3. meddis3</td>
</tr>
<tr>
<td>4. meddis4</td>
</tr>
<tr>
<td>5. meddis5</td>
</tr>
<tr>
<td>6. meddis6</td>
</tr>
<tr>
<td>7. meddis7</td>
</tr>
<tr>
<td>8. meddis8</td>
</tr>
<tr>
<td>9. meddis9</td>
</tr>
<tr>
<td>10. meddis10</td>
</tr>
<tr>
<td>11. meddis11</td>
</tr>
<tr>
<td>12. meddis12</td>
</tr>
</tbody>
</table>

Pain Medication Data Collection Table
(only pain medication prescribed at discharge needs to be collected)

<table>
<thead>
<tr>
<th>No pain medication</th>
<th>pmed_dis___0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methadone</td>
<td>pmed_dis___1</td>
</tr>
<tr>
<td>Codeine</td>
<td>pmed_dis___2</td>
</tr>
<tr>
<td>Hydrocodon (Norco, Vicoden)</td>
<td>pmed_dis___3</td>
</tr>
<tr>
<td>Oxycodone (Percodet, OxyContin)</td>
<td>pmed_dis___4</td>
</tr>
<tr>
<td>Hydromorphone (Dilaudid)</td>
<td>pmed_dis___5</td>
</tr>
<tr>
<td>Fentanyl (Duragesic)</td>
<td>pmed_dis___6</td>
</tr>
<tr>
<td>Morphine</td>
<td>pmed_dis___7</td>
</tr>
<tr>
<td>Acetaminophen with codeine (Tylenol #3)</td>
<td>pmed_dis___8</td>
</tr>
<tr>
<td>Gabapentin (Neurontin)</td>
<td>pmed_dis___9</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>pmed_dis___10</td>
</tr>
<tr>
<td>Unknown</td>
<td>pmed_dis___99</td>
</tr>
</tbody>
</table>
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.”
We’re going to get started with the survey. Please let me know at any time if you have any questions.

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

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

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

Let’s get started. The first section is about your current health.
### Health Status

1. Have you ever had another major injury requiring hospitalization besides your burn injury?  
   **majhospdis**

**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.*

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hearing loss? hlossdis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>2. Change in voice? voicedis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>3. Vision problems not corrected by glasses or contact lenses? visiondis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>4. Eyelid problems? eyeliddis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>5. Excessive tearing of the eyes? teardis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>6. Difficulty with memory? memorydis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>7. Difficulty with thought processing? thoughtdis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>8. Numbness, pins and needles or burning sensations in your burn scar? numbscdis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>9. Numbness, pins and needles or burning sensations in your hands? numbhdis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>10. Numbness, pins and needles or burning sensations in your feet? numbfdis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>11. Trouble with your balance? tbalandis</td>
<td>☐ Yes=1  ☐ No=2  ☐ Skipped/Refused=88</td>
</tr>
<tr>
<td></td>
<td>☐ Don’t know/Missing=99</td>
</tr>
<tr>
<td>Question</td>
<td>Codebook Name</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>12. Varicose veins?</td>
<td>varveindis</td>
</tr>
<tr>
<td>13. Swollen feet or legs?</td>
<td>swflegdis</td>
</tr>
<tr>
<td>14. Swollen hands or arms?</td>
<td>swharmdis</td>
</tr>
<tr>
<td>15. Difficulty breathing when doing your regular daily activities?</td>
<td>difbrergdis</td>
</tr>
<tr>
<td>16. Difficulty breathing when exercising?</td>
<td>difbreexdis</td>
</tr>
<tr>
<td>17. Skin cancer?</td>
<td>skincancdis</td>
</tr>
<tr>
<td>18. Joint pain?</td>
<td>jpaindis</td>
</tr>
<tr>
<td>19. Have you ever been pregnant or fathered a child?</td>
<td>preg_fathdis</td>
</tr>
<tr>
<td>20. Blood clots in legs or lungs?</td>
<td>bcleglungdis</td>
</tr>
<tr>
<td>21. Cold intolerance?</td>
<td>cintoldis</td>
</tr>
<tr>
<td>22. Excessive sweating?</td>
<td>exsweatdis</td>
</tr>
<tr>
<td>23. Difficulty in hot environments?</td>
<td>difhotdis</td>
</tr>
</tbody>
</table>
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

2. In the past 12 months, did you take medication for being, worried, tense, or anxious? **wmmed_pre**
   1. [ ] Yes
   2. [ ] No

3. In the past 12 months, did you take medication for being sad, empty, or depressed? **smed_pre**
   1. [ ] Yes
   2. [ ] No

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.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree =1</th>
<th>Disagree =2</th>
<th>Slightly disagree =3</th>
<th>Neither agree nor disagree =4</th>
<th>Slightly agree =5</th>
<th>Agree =6</th>
<th>Strongly agree =7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In the 4 weeks before my burn, in most ways my life was close to ideal:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sl1_pre</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. In the 4 weeks before my burn, the conditions of my life were excellent:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sl2_pre</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. In the 4 weeks before my burn, I was satisfied with my life: sl3_pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. In the 4 weeks before my burn, I had gotten the important things I wanted in life: sl4_pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
5. In the 4 weeks before my burn, if I could have lived my life over, I would have changed almost nothing: 

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<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>sl5_pre</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**BMS Adult Codebook Form I**

NewMSID_________

88/Refused
99/Unknown

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

**CIQ: PRE-BURN**

**During the 4 weeks before your burn:**

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

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tbody>
<tr>
<td><strong>cia2_pre</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Yourself alone
2. Yourself and someone else
3. Someone else

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

2: Shopping 

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ci3_pre</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ci4_pre</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

4: Visiting friends or relatives 

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ci5_pre</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

**During the 4 weeks before your burn:**

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

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ci6_pre</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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? 

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ci7_pre</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Yes
2. No

88/Refused
99/Unknown
Variable names and information indicated in red. Numbers for response categories correspond to codes unless otherwise noted.

**PHQ-9 #9: PRE-BURN**

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

1. In the two weeks before your burn, how often were you bothered by thoughts that you would be better off dead or of hurting yourself in some way? phq9_9_pre
   - 1. □ Not at all =0
   - 2. □ Several days =1
   - 3. □ More than half the days =2
   - 4. □ Nearly every day =3

*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
   
<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXCELLENT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VERY GOOD</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>GOOD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FAIR</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>POOR</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

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

   a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? vr12pre2a
   - YES, LIMITED A LOT
   - YES, LIMITED A LITTLE
   - NO, NOT LIMITED AT ALL
   
<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES, LIMITED A LOT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES, LIMITED A LITTLE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO, NOT LIMITED AT ALL</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. The following questions are about activities you might do during a typical day. Did **your health limit you** in these activities before your burn injury? If so, how much?

<table>
<thead>
<tr>
<th></th>
<th>YES, LIMITED A LOT</th>
<th>YES, LIMITED A LITTLE</th>
<th>NO, NOT LIMITED AT ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>b. Climbing <strong>several</strong> flights of stairs? vr12pre2b</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

88/Refused  
99/Unknown

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

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<tr>
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</thead>
<tbody>
<tr>
<td>a. <strong>Accomplished less</strong> than you would like. vr12pre3a</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. <strong>Were limited in the kind</strong> of work or other activities. vr12pre3b</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

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

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</thead>
<tbody>
<tr>
<td>a. <strong>Accomplished less</strong> than you would like. vr12pre4a</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. <strong>Didn't do work or other activities as carefully</strong> as usual. vr12pre4b</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>NOT AT ALL</th>
<th>A LITTLE BIT</th>
<th>MODERATELY</th>
<th>QUITE A BIT</th>
<th>EXTREMELY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

88/Refused  
99/Unknown

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

6. How much of the time **during the 4 weeks before your burn**:
Variable names and information about variables appear in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Adult Data Dictionary Form I

NewMSID_________

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>vr12pre6a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Did you feel calm and peaceful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>vr12pre6b</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Did you have a lot of energy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>vr12pre6c</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Did you feel downhearted and blue?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

7. During the 4 weeks before your burn, how much of the time did your physical health or emotional problems interfere with your social activities (like visiting with friends, relatives, etc.)? _ vr12pre7_

<table>
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</tbody>
</table>
| VR-12 Mental Health Component Score: Pre Total Score Variable: mcs_vr12_pre

Pre-Injury Demographics _ VR-12 Physical Health Component Score: Pre Total Score Variable: pcs_vr12_pre

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

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
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) 

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

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

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

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.”

How many people are in your household? ________

(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? _____

(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”)

How many months
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: __________

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

1 - Executive, Administrative, And Managerial; 2 - Professional Specialty; 3 - Technicians And Related Support; 4 - Sales; 5 - Administrative Support Including Clerical; 6 - Private Household; 7 - Protective Service; 8 - Service, Except Protective And Household; 9 - Farming, Forestry, And Fishing; 10 - Precision Production, Craft, And Repair; 11 - Machine Operators, Assemblers, And Inspectors; 12 - Transportation And Material Moving; 13 - Handlers, Equipment Cleaners, Helpers, And Laborers; 14 - Military Occupations; 77 – Not Applicable; 88 – Declined to Answer/Refused; 99 – Unknown

8. What was your employment status at the time of your burn? employpre
   1. ☐ Working (Interviewer instructions: continue with next question)
   2. ☐ Not working (looking for work)
   3. ☐ Not working (not looking for work)
   4. ☐ Homemaker/caregiver
   5. ☐ Volunteer
   6. ☐ Retired
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown

Old variable was named “employ”.

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

9. Before your burn, about how many hours a week did you work for pay? ______ hpaypre
   (Interviewer Instructions: fill in hours)
   777. ☐ Not applicable (not employed)
   888. ☐ Declined to answer/Refused
   999. ☐ Unknown

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

10. Approximately what was your individual income in the last full year before your burn injury? inccatpre
    1. ☐ Less than $25,000
    2. ☐ $25,000-$40,999
    3. ☐ $41,000-$55,999
    4. ☐ $56,000-$70,999
    88. ☐ Declined to answer/Refused
    99. ☐ Unknown
Variable names and information about variables appear in red. Numbers for response categories correspond to codes unless otherwise noted.

**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?  
   1. In school  
   2. Not in school

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

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

12. If you were not working or going to school at the time of your burn injury, why not?  
   1. Burn related (This response is N/A for discharge)  
   2. Medical problems other than your burn injury  
   3. Problems with employer  
   4. Emotional/social  
   5. Legal/jail  
   6. Substance abuse  
   7. Personal choice  
   8. Other  
   9. Retired  
   10. Homemaker/caregiver  
   11. Unemployed but actively seeking employment  
   77. Not applicable (working or going to school)

**Post-Injury Section**

All the questions I just asked you were about the time before your burn injury. Now I’m going to ask you some of the same questions I just asked you, but this time I want you to answer about
the time since the burn injury. As a reminder, some of these questions can feel repetitive but it’s part of the research process. Thank you for your patience.

**PHQ-9 #9: DISCHARGE**

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

1. In the past 7 days, or since your burn if you were injured less than 7 days ago, how often have you been bothered by thoughts that you would be better off dead or of hurting yourself in some way?  
   
   1. □ Not at all =0  
   2. □ Several days =1  
   3. □ More than half the days =2  
   4. □ Nearly every day =3  

*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

<table>
<thead>
<tr>
<th>EXCELLENT</th>
<th>VERY GOOD</th>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>
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?

<table>
<thead>
<tr>
<th>YES, LIMITED A LOT</th>
<th>YES, LIMITED A LITTLE</th>
<th>NO, NOT LIMITED AT ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? vr12dis2a</td>
<td></td>
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<tr>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>b. Climbing several flights of stairs? vr12dis2b</td>
<td></td>
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<tr>
<td>1</td>
<td>2</td>
<td>3</td>
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</tbody>
</table>

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?

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</thead>
<tbody>
<tr>
<td>a. Accomplished less than you would like. vr12dis3a</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>b. Were limited in the kind of work or other activities. vr12dis3b</td>
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<td></td>
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<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

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)?

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<tbody>
<tr>
<td>a. Accomplished less than you would like. vr12dis4a</td>
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<td>1</td>
<td>2</td>
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</tr>
<tr>
<td>b. Didn't do work or other activities as carefully as usual. vr12dis4b</td>
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<td>1</td>
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<td>4</td>
<td>5</td>
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</tbody>
</table>

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
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:

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<td>6</td>
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</table>

   a. Have you felt calm and peaceful? vr12dis6a

   b. Did you have a lot of energy? vr12dis6b

   c. Have you felt downhearted and blue? vr12dis6c

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

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</table>

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

Now I have a few questions about your alcohol and drug use. As a reminder, you can skip any question you don’t want to answer. You don’t need the response key for this section.

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

In the past year...

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

1. Have you felt you needed to Cut down on your drinking? □ Yes (1)    □ No (0)

2. Have people Annoyed you by criticizing your drinking? □ Yes (1)    □ No (0)

3. Have you ever felt Guilty about drinking? □ Yes (1)    □ No (0)
4. Have you ever felt you needed a drink first thing in the morning (Eye-opener) to steady your nerves or to get rid of a hangover? ☐ Yes (1) ☐ No (0)

**CAGE Drug use:**
*Interviewer Instructions:* If clarification is needed, say, “We are interested in learning more about use of drugs like marijuana, crack or heroin; or about prescription drugs like pain killers or stimulants that were not prescribed to you; or chemicals you might have inhaled or 'huffed'. We also want to know if sometimes you took more than you should have of any drugs that have been prescribed to you.”
*Interviewer Instructions:* If the participants states they do not use drugs after the first question, you can fill in “No” for all four questions and skip to the next section.

In the past year…

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

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

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

4. Have you ever felt you needed to use drugs first thing in the morning (Eye-opener) to steady your nerves or to get rid of a hangover? ☐ Yes (1) ☐ No (0)

**These items are not asked aloud by data collectors.**

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

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

Patient’s history of drug abuse in the last 12 months drugabu

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

**Itch scale:**

*The next questions are about itching since your burn injury.*

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

1. ☐ Yes
2. ☐ No *(Interviewer Instructions: skip to CAGE Alcohol Use on page 17)*
88. ☐ Declined to answer/Refused
99. ☐ Unknown

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

1. ☐ Less than 6 hours a day
2. ☐ 6-12 hours a day
3. ☐ 12-18 hours a day
4. ☐ 18-23 hours a day
5. ☐ All day

88. ☐ Declined to answer/Refused
99. ☐ Unknown
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Adult Codebook Form I**

NewMSID_________

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)

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

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

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

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

**DEMOGRAPHICS**

This is the last section of the survey.

*Interviewer Instructions: Use medical record for #1 and #2. Skip these questions unless self-report is best source, and record answer onto the Form I Medical Record Abstraction Form along with source of data. If disposition (#2, below) is not clear on Medical Record, clarify with participant.*

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

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

   1. □ Non-intentional employment related
   2. □ Non-intentional non-work related *(Interviewer Instructions: choose this category if employment and/or recreation do not apply)*
   3. □ Non-intentional recreation
   4. □ Non-intentional non-specified *(Interviewer Instructions: choose this category if there is no information on circumstances other than non-intentional)*
   5. □ Suspected assault-domestic
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.

2. After your discharge, where will you be living? (Choose only one) dislivsit
   1. □ House
   2. □ Apartment
   3. □ Mobile home
   4. □ Institution
   88. □ Declined to answer/Refused
   99. □ Unknown
5. □ Homeless
6. □ Other

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

3. Who will you be living with after hospital discharge? (Choose all that apply)
   1. □ Alone livhisdis___1
   2. □ Spouse/partner/significant other livhisdis___2
   3. □ Friend livhisdis___3
   4. □ Parent or step-parent livhisdis___4
   5. □ Other relative (siblings, grandparents) livhisdis___5
   6. □ Others, not part of family livinga___6
   7. □ Guardian livhisdis___7
   8. □ Young children livhisdis___8
   9. □ Adult children livhisdis___9

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
   2. □ 2 years
   3. □ 3 years
   4. □ 4 years
   5. □ 5 years
   6. □ 6 years
   7. □ 7 years
   8. □ 8 years
   9. □ 9 years
   10. □ 10 years
   88. □ Declined to answer/Refused livhisdis___88
   99. □ Unknown livhisdis___99
11. □ 11 or 12 years; no diploma  
12. □ High school diploma  
13. □ Work towards Associate’s degree  
14. □ Associate’s degree  
15. □ Work towards Bachelor’s degree  
16. □ Bachelor's degree  
17. □ Work towards Master's degree  
18. □ Master's degree  
19. □ Work towards doctorate level degree  
20. □ Doctoral level degree  
66. □ Other

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

5. Did you earn a GED instead of graduating from high school? geddis  
1. □ No  
2. □ Yes  
77. □ Not applicable (high school diploma or higher)

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

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

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

9. Have you ever served in the military? mildis
<p>| | | |</p>
<table>
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<tbody>
<tr>
<td>1.</td>
<td>No</td>
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<tr>
<td>2.</td>
<td>Yes</td>
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</table>

88. □ Decline to answer/Refused
99. □ Unknown

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

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

Indicate time survey ended: ____________
### Please answer each question as it relates to your current health:

<table>
<thead>
<tr>
<th>Question</th>
<th>Codebook</th>
<th>Yes</th>
<th>No</th>
<th>Skipped/Refused</th>
<th>Don’t know/Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hearing loss? <strong>hlossdis</strong></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>2. Change in voice? <strong>voicedis</strong></td>
<td></td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>3. Vision problems not corrected by glasses or contact lenses? <strong>visiondis</strong></td>
<td></td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
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<tr>
<td>4. Eyelid problems? <strong>eyeliddis</strong></td>
<td></td>
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<tr>
<td>5. Excessive tearing of the eyes? <strong>teardis</strong></td>
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<td>☐</td>
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<tr>
<td>6. Difficulty with memory? <strong>memorydis</strong></td>
<td></td>
<td>☐</td>
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<td>7. Difficulty with thought processing? <strong>thoughtdis</strong></td>
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<tr>
<td>8. Numbness, pins and needles or burning sensations in your burn scar? <strong>numbscdis</strong></td>
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<td>☐</td>
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<td>9. Numbness, pins and needles or burning sensations in your hands? <strong>numbhdis</strong></td>
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<td>10. Numbness, pins and needles or burning sensations in your feet? <strong>numbfdis</strong></td>
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<td>11. Trouble with your balance? <strong>tbalandis</strong></td>
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<td>12. Varicose veins? <strong>varveindis</strong></td>
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<tr>
<td>Question</td>
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<td>Don't know/Missing</td>
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<td>13. Swollen feet or legs?</td>
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<tr>
<td>swflegdis</td>
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<td>14. Swollen hands or arms?</td>
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<td>swharmdis</td>
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<td>15. Difficulty breathing when doing your regular daily activities?</td>
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<td>16. Difficulty breathing when exercising?</td>
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<td>difbreexdis</td>
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<td>17. Skin cancer?</td>
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<td>skincancdis</td>
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<td>18. Joint pain?</td>
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<td>jpaindis</td>
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<td>19. Have you had any urinary tract infections (bladder infections or UTIs) in the past year? About how many?</td>
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<td>20. Blood clots in legs or lungs?</td>
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<td>bclelegtungdis</td>
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<td>21. Cold intolerance?</td>
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<td>cintoldis</td>
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<td>22. Excessive sweating?</td>
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<td>exsweatdis</td>
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<td>23. Difficulty in hot environments?</td>
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<td>difhotdis</td>
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</tbody>
</table>
Date Medication Data Collected: ____ / ____ / ____

1. Follow-up period
   1. [ ] 6-month follow-up  
      Pain medication data collection added to forms in 2015. This 
      form is not given to participants but collected using the medical 
      record during the follow-up window.
   2. [ ] 12-month follow-up
   3. [ ] 24-month follow-up
   4. [ ] 5 year follow-up
   5. [ ] 10 year follow-up
   6. [ ] 15 year follow-up
   7. [ ] 20 year follow-up

Item with common pain medications added in July 2016 (check all that apply)

Pain Medication Data Collection Table (only pain medication prescribed within the data collection window 
needs to be collected)

<p>| | | | | | | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>0. □ No pain medication pmed_fup__0; 0=not checked; 1=checked</td>
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<tr>
<td>1. □ Methadone pmed_fup__1; 0=not checked; 1=checked</td>
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<tr>
<td>2. □ Codeine pmed_fup__2; 0=not checked; 1=checked</td>
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<tr>
<td>3. □ Hydrocodon (Norco, Vicoden) pmed_fup__3; 0=not checked; 1=checked</td>
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<td>4. □ Oxycodone (Percodet, OxyContin) pmed_fup__4; 0=not checked; 1=checked</td>
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<td>5. □ Hydromorphone (Dilaudid) pmed_fup__5; 0=not checked; 1=checked</td>
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<td>6. □ Fentanyl (Duragesic) pmed_fup__6; 0=not checked; 1=checked</td>
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<td>7. □ Morphine pmed_fup__7; 0=not checked; 1=checked</td>
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<tr>
<td>8. □ Acetaminophen with codeine (Tylenol #3) pmed_fup__8; 0=not checked; 1=checked</td>
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<tr>
<td>9. □ Gabapentin (Neurontin) pmed_fup__9; 0=not checked; 1=checked</td>
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<tr>
<td>99. □ Unknown pmed_fup__99; 0=not checked; 1=checked</td>
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</tbody>
</table>

Name of Pain Medication (prescribed in data collection window), if other than above

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1.  med1</td>
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<tr>
<td>2.  med2</td>
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<td>3.  med3</td>
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<tr>
<td>4.  med4</td>
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<td>5.  med5</td>
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<td>6.  med6</td>
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<td>7.  med7</td>
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<td>8.  med8</td>
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<td>9.  med9</td>
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<td>10. med10</td>
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<td>11. med11</td>
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<tr>
<td>12. med12</td>
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</tbody>
</table>
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
   9. ☐ Incarcerated
   10. ☐ Still in hospital (not discharged yet)
   11. ☐ Unable to travel for assessment

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

Option 14 added with new forms in 2015
Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant. Have the updated Patient Status form with you to help with the interview.

If a participant doesn’t want to answer any item or doesn’t know the answer, circle “88” (Declined to Answer/Refused) or “99” (Unknown) next to that item.

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

Introduction script:
Hi my name is ____ and I am calling from _____ to ask you some questions about how you have been doing (since your injury)… or (since we last spoke with you on (last follow-up date)).

Thank you for continuing to participate in our study of 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.
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
      2. □ No
      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
   2. □ No
   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? psychther
   1. □ Yes
   2. □ No
   88. □ Declined to answer/Refused
   99. □ Unknown
   Previous variable, psych, used this wording:
   FT27. Since your last follow-up, have you received psychological or peer support therapy for your burn?
   New variables, splitting psych into two questions, added in 2015.

5. Since your last interview, have you spoken with other burn survivors to get support for problems related to your burn injury? peersup
   1. □ Yes
   2. □ No
   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
   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
   Added in 2015
Interviewer Instructions: if participant indicates that services were received but that those services were not occupational and/or physical therapy, skip to #10, surgery item, on page 6.

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

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

numserv
Added in 2015
Since your last interview, where did you receive your outpatient occupational or physical burn therapy? ther_brn_cntr
8. Burn center?
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable (no OT/PT received)

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)

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)

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)

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_num surg (77—Not applicable (no surgeries)
13. Which burn related surgeries have you had since your last interview? (Choose all that apply)

1. Surgery for open wounds surgtype_1
2. Surgery for joint contractures surgtype_2
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)

Source of type of surgeries: Self-report - Medical record
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)

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 numugtrfu_8; 0=not checked; 1=checked
9. Yes, digits only left numuglrfu_9; 0=not checked; 1=checked
10. Yes, digits only bilateral numugtrbfu_10; 0=not checked; 1=checked

Notes:
New variable added with new Forms in 2015

88. Declined to answer/Refused
99. Unknown
2. Have you had a lower extremity amputation due to burn injury since your last interview? (Choose all that apply)

Interviewer instructions: ask as open ended and then mark the correct response.

1.  □ No amputfu2__1; 0=not checked; 1=checked
2.  □ Yes, above knee right amputfu2__2; 0=not checked; 1=checked
3.  □ Yes, above knee left amputfu2__3; 0=not checked; 1=checked
4.  □ Yes, above knee bilateral amputfu2__4; 0=not checked; 1=checked
5.  □ Yes, below knee right amputfu2__5; 0=not checked; 1=checked
6.  □ Yes, below knee left amputfu2__6; 0=not checked; 1=checked
7.  □ Yes, below knee bilateral amputfu2__7; 0=not checked; 1=checked
8.  □ Yes, digits only right numldgrfu ______________ (fill in # of digits) amputfu2__8; 0=not checked; 1=checked
9.  □ Yes, digits only left 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

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  88. □ Declined to answer/Refused
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 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:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hearing loss?</td>
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</tr>
<tr>
<td>2. Change in voice?</td>
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<tr>
<td>3. Vision problems not corrected by glasses or contact lenses?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>4. Eyelid problems?</td>
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<tr>
<td>5. Excessive tearing of the eyes?</td>
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<tr>
<td>6. Difficulty with memory?</td>
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<tr>
<td>7. Difficulty with thought processing?</td>
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</tbody>
</table>
8. Numbness, pins and needles or burning sensations in your burn scar?
   □ Yes □ No □ Don't know

9. Numbness, pins and needles or burning sensations in your hands?
   □ Yes □ No □ Don't know

10. Numbness, pins and needles or burning sensations in your feet?
    □ Yes □ No □ Don't know

11. Trouble with your balance?
    □ Yes □ No □ Don't know

12. Varicose veins?
    □ Yes □ No □ Don't know

13. Swollen feet or legs?
    □ Yes □ No □ Don't know

14. Swollen hands or arms?
    □ Yes □ No □ Don't know

15. Difficulty breathing when doing your regular daily activities?
    □ Yes □ No □ Don't know

16. Difficulty breathing when exercising?
    □ Yes □ No □ Don't know

17. Skin cancer?
    □ Yes □ No □ Don't know

18. Joint pain?
    □ Yes □ No □ Don't know

19. Have you been pregnant or fathered a child since your last interview?
    □ Yes □ No □ Don't know

20. Blood clots in legs or lungs?
    □ Yes □ No □ Don't know

21. Cold intolerance?
    □ Yes □ No □ Don't know

22. Excessive sweating?
    □ Yes □ No □ Don't know

23. Difficulty in hot environments?
    □ Yes □ No □ Don't know

---

**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
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? \( \text{itch1} \)
   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: \( \text{itch2} \)
   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? \( \text{itch3} \)
   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:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not applicable = 0</th>
<th>Never affects = 1</th>
<th>Occasionally delays = 2</th>
<th>Frequently delays = 3</th>
<th>Delays falling asleep and occasionally wakes me up at night = 4</th>
<th>Delays falling asleep and frequently wakes me up at night = 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Leisure/social:</td>
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<tr>
<td>Housework/errands:</td>
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<tr>
<td>Work/school</td>
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</tbody>
</table>

88 / 99

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

VR-12:

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

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

**Interviewer Instructions:** Circle one number on each line

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

<table>
<thead>
<tr>
<th>EXCELLENT</th>
<th>VERY GOOD</th>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th>YES, LIMITED A LOT</th>
<th>YES, LIMITED A LITTLE</th>
<th>NO, NOT LIMITED AT ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>88/Refused</th>
<th>99/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

b. Climbing several flights of stairs? vr12_2b

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>88/Refused</th>
<th>99/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

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

a. Accomplished less than you would like. vr12_3a

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>88/Refused</th>
<th>99/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>88/Refused</th>
<th>99/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

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

a. Accomplished less than you would like. vr12_4a

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>88/Refused</td>
<td>99/Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>88/Refused</th>
<th>99/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- NO, NONE OF THE TIME (1)
- YES, A LITTLE OF THE TIME (2)
- YES, SOME OF THE TIME (3)
- YES, MOST OF THE TIME (4)
- YES, ALL OF THE TIME (5)

b. Didn’t do work or other activities as carefully as usual. vr12_4b

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

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

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

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

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

- ALL OF THE TIME (1)
- MOST OF THE TIME (2)
- A GOOD BIT OF THE TIME (3)
- SOME OF THE TIME (4)
- A LITTLE OF THE TIME (5)
- NONE OF THE TIME (6)

a. Have you felt calm and peaceful? vr12_6a

b. Did you have a lot of energy? vr12_6b

c. Have you felt downhearted and blue? vr12_6c

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

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

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

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

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

- MUCH BETTER
- SLIGHTLY BETTER
- ABOUT THE SAME
- SLIGHTLY WORSE
- MUCH WORSE

Version 3/2015
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Adult Codebook Form II**

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

- N/A: 6 or 12 month interview

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

<table>
<thead>
<tr>
<th>MUCH BETTER</th>
<th>SLIGHTLY BETTER</th>
<th>ABOUT THE SAME</th>
<th>SLIGHTLY WORSE</th>
<th>MUCH WORSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

- N/A: 6 or 12 month interview

Total VR-12 Physical Health Component Score: pcs_vr12
Total VR-12 Mental Health Component Score: mcs_vr12

**PHQ-9 #9**

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

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

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Not at all</td>
<td>=0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Several days</td>
<td>=1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>More than half the days</td>
<td>=2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Nearly every day</td>
<td>=3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**

<table>
<thead>
<tr>
<th></th>
<th>Without any difficulty</th>
<th>With a little difficulty</th>
<th>With some difficulty</th>
<th>With much difficulty</th>
<th>Unable to do=1</th>
</tr>
</thead>
</table>
### Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

#### BMS Adult Codebook Form II

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you able to do chores such as vacuuming or yard work? pfa11</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>2. Are you able to go up and down stairs at a normal pace? pfa21</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>3. Are you able to go for a walk of at least 15 minutes? pfa23</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>4. Are you able to run errands and shop? pfa53</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>

**PROMIS Physical Function T-Score: pftscore**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. I felt fearful edanx01</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>6. I found it hard to focus on anything other than my anxiety edanx40</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>7. My worries overwhelmed me edanx41</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>8. I felt uneasy edanx53</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>

**PROMIS Anxiety T-Score: anxtscore**

#### ANXIETY

<table>
<thead>
<tr>
<th>In the past 7 days...</th>
<th>Never=1</th>
<th>Rarely=2</th>
<th>Sometimes=3</th>
<th>Often=4</th>
<th>Always=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. I felt fearful edanx01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I found it hard to focus on anything other than my anxiety edanx40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. My worries overwhelmed me edanx41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I felt uneasy edanx53</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PROMIS Depression T-Score: deptscore**

#### DEPRESSION

<table>
<thead>
<tr>
<th>In the past 7 days...</th>
<th>Never=1</th>
<th>Rarely=2</th>
<th>Sometimes=3</th>
<th>Often=4</th>
<th>Always=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. I felt worthless eddep04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I felt helpless eddep06</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I felt depressed eddep29</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I felt hopeless eddep41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**FATIGUE**

<table>
<thead>
<tr>
<th>Question</th>
<th>Codebook Form II</th>
<th>13. I feel fatigued</th>
<th>14. I have trouble starting things because I am tired</th>
<th>15. How run-down did you feel on average?</th>
<th>16. How fatigued were you on average?</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the past 7 days...</td>
<td></td>
<td>not at all=1</td>
<td>a little bit=2</td>
<td>somewhat=3</td>
<td>quite a bit=4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>very much=5</td>
</tr>
<tr>
<td>13. I feel fatigued</td>
<td>hi7</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>14. I have trouble starting things because I am tired</td>
<td>an3</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

**In the past 7 days**

15. How run-down did you feel on average?
16. How fatigued were you on average?

**SLEEP DISTURBANCE**

<table>
<thead>
<tr>
<th>Question</th>
<th>Codebook Form II</th>
<th>17. My sleep quality was</th>
<th>18. My sleep was refreshing</th>
<th>19. I had a problem with my sleep</th>
<th>20. I had difficulty falling asleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 7 days...</td>
<td></td>
<td>very poor=5</td>
<td>poor=4</td>
<td>fair=3</td>
<td>good=2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>very good=1</td>
</tr>
<tr>
<td>17. My sleep quality was</td>
<td>sleep109</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

| In the past 7 days...                                                    |                  | not at all              | a little bit                | somewhat                        | quite a bit                        |
|                                                                          |                  |                          |                             |                                  |                                    |
| 18. My sleep was refreshing                                             | sleep116         | [ ]                     | [ ]                         | [ ]                               | [ ]                                 |
| 19. I had a problem with my sleep                                       | sleep20          | [ ]                     | [ ]                         | [ ]                               | [ ]                                 |
| 20. I had difficulty falling asleep                                      | sleep44          | [ ]                     | [ ]                         | [ ]                               | [ ]                                 |

**ABILITY TO PARTICIPATE IN SOCIAL ROLES AND ACTIVITIES**

<table>
<thead>
<tr>
<th>Question</th>
<th>Codebook Form II</th>
<th>21. I have trouble doing all of my regular leisure activities with others</th>
<th>22. I have trouble keeping up with my family responsibilities</th>
<th>23. I have trouble doing all of my usual work (include work at home)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>never=5</td>
<td>rarely=4</td>
<td>sometimes=3</td>
</tr>
<tr>
<td>21. I have trouble doing all of my regular leisure activities with others</td>
<td>srpper11</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>22. I have trouble keeping up with my family responsibilities</td>
<td>srpper22</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>23. I have trouble doing all of my usual work (include work at home)</td>
<td>srpper23</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

**PROMIS Fatigue T-Score: fattscore**

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

**PROMIS Ability to Participate in Social Roles T-Score: socroltscore**
24. I have trouble keeping in touch with others srppcr43r1

### PAIN INTERFERENCE

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>Not at all=1</th>
<th>A little bit=2</th>
<th>Somewhat=3</th>
<th>Quite a bit=4</th>
<th>Very much =5</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. How much did pain interfere with your day to day activities? painin9</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>26. How much did pain interfere with work around the home? painin22</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>27. How much did pain interfere with your ability to participate in social activities? painin31</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>28. How much did pain interfere with your household chores? painin34</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

PROMIS Pain Interference T-Score: paintscore

### Pain Intensity

<table>
<thead>
<tr>
<th>No pain</th>
<th>Worst imaginable pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 7 days…</td>
<td>0</td>
</tr>
<tr>
<td>29. How would you rate your pain on average? global07</td>
<td>☐</td>
</tr>
</tbody>
</table>

### 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.

<table>
<thead>
<tr>
<th>Lately…</th>
<th>Never=1</th>
<th>Rarely=2</th>
<th>Sometimes=3</th>
<th>Often=4</th>
<th>Always=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Because of my injury, some people avoided me. nqstg02</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

<table>
<thead>
<tr>
<th>Question</th>
<th>Extreme(ly) =0</th>
<th>Quite a bit =1</th>
<th>Moderate(ly) =2</th>
<th>A little bit =3</th>
<th>None (not at all) =4</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Because of my injury, I felt left out of things. nqstg04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Because of my injury, people avoided looking at me. nqstg08</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I felt embarrassed about my injury. nqstg16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Because of my injury, some people seemed uncomfortable with me. nqstg01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I felt embarrassed because of my physical limitations. nqstg17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Because of my injury, people were unkind to me. nqstg05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Some people acted as though it was my fault I have this injury. nqstg21</td>
<td></td>
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</tr>
</tbody>
</table>

NeuroQOL Stigma SF T-Score: nqstgtscore

**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.

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

To what extent does each of the following statements describe you?

<table>
<thead>
<tr>
<th>Extreme(ly) =0</th>
<th>Quite a bit =1</th>
<th>Moderate(ly) =2</th>
<th>A little bit =3</th>
<th>None (not at all) =4</th>
</tr>
</thead>
</table>
BH10. I am troubled by feelings of loneliness. bshs_10
BH11. I often feel sad or blue. bshs_11
BH12. At times, I think I have an emotional problem. bshs_12
BH13. I am not interested in doing things with my friends. bshs_13
BH14. I do not enjoy visiting people. bshs_14
BH15. I have no one to talk to about my problems. bshs_15
BH16. I have feelings of being trapped or caught. bshs_16
BH17. My injury has put me further away from my family. bshs_17

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
BH19. I do not like the way my family acts around me. bshs_19
BH20. My family would be better off without me. bshs_20
BH21. I feel frustrated because I cannot be sexually aroused as well as I used to. bshs_21
BH22. I am simply not interested in sex anymore. bshs_22
BH23. I no longer hug, hold, or kiss. bshs_23
BH24. Sometimes, I would like to forget that my appearance has changed. bshs_24
BH25. I feel that my burn is unattractive to others. bshs_25
BH26. My general appearance really bothers me. bshs_26
BH27. The appearance of my scars bothers me. bshs_27
BH28. Being out in the sun bothers me. bshs_28
BH29. Hot weather bothers me. bshs_29
BH30. I cannot get out and do things in hot weather. bshs_30
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

| 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 |

BSHS Heat Sensitivity Score: bshs_hs
BSHS Affect Score: bshs_af
BSHS Hand Function Score: bshs_hf
BSHS Treatment Regimen Score: bshs_tr
BSHS Work Score: bshs_wo

BSHS Sexuality Score: bshs_se

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 Cut down on your drinking? □ Yes (1) □ No (0)

2. Have people Annoyed you by criticizing your drinking? □ Yes (1) □ No (0)

3. Have you ever felt Guilty about drinking? □ Yes (1) □ No (0)

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

CAGE Drug use:

**Interviewer instructions:** If clarification is needed, say, “We are 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)
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 **Cut down on your drug use?** [ ] Yes (1) [ ] No (0)
2. Have people **Annoyed you by criticizing your drug use?** [ ] Yes (1) [ ] No (0)
3. Have you ever felt **Guilty about your drug use?** [ ] Yes (1) [ ] No (0)
4. Have you ever felt you needed to use drugs first thing in the morning (**Eye-opener**) to steady your nerves or to get rid of a hangover? [ ] Yes (1) [ ] No (0)

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

Patient’s history of alcohol abuse in the past year (or since last interview): etohabufup
- [ ] Yes (C-A-G-E=2,3,4) 88. [ ] Declined to answer/Refused
- [ ] No (C-A-G-E=0,1) 99. [ ] Unknown

Patient’s history of drug abuse the past year (or since last interview): drugabufup
- [ ] Yes (C-A-G-E=2,3,4) 88. [ ] Declined to answer/Refused
- [ ] 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.

<table>
<thead>
<tr>
<th>How much have you been bothered by...</th>
<th>Not at all (1)</th>
<th>A little bit (2)</th>
<th>Moderately (3)</th>
<th>Quite a bit (4)</th>
<th>Extremely (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Repeated, disturbing <strong>memories, thoughts, or images</strong> of your burn injury? pclc_1</td>
<td>✔️</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Repeated, disturbing <strong>dreams</strong> of your burn injury? pclc_2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Suddenly <strong>acting or feeling</strong> as if your burn injury were <strong>happening</strong> again (as if you were reliving it)? pclc_3</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Feeling <strong>very upset</strong> when something <strong>reminded</strong> you of your burn injury? pclc_4</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Having <strong>physical reactions</strong> (e.g., heart pounding, trouble breathing, or sweating) when something <strong>reminded</strong> you of your burn injury? pclc_5</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Avoid <strong>thinking about or talking about</strong> your burn injury or avoid <strong>having feelings</strong> related to it? pclc_6</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Avoid <strong>activities or situations</strong> because they <strong>remind you</strong> of your burn injury? pclc_7</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Adult Codebook Form II

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Response Options</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.</td>
<td>Trouble remembering important parts of your burn injury? pclc_8</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Loss of interest in things that you used to enjoy? pclc_9</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Feeling distant or cut off from other people? pclc_10</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Feeling emotionally numb or being unable to have loving feelings for those close to you? pclc_11</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Feeling as if your future will somehow be cut short? pclc_12</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Trouble falling or staying asleep? pclc_13</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Feelling irritable or having angry outbursts? pclc_14</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Having difficulty concentrating? pclc_15</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Being “super alert” or watchful on guard? pclc_16</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Feeling jumpy or easily startled? pclc_17</td>
<td>☐ ☐ ☐ ☐</td>
<td></td>
</tr>
</tbody>
</table>

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

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

   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

3: Leisure activities such as movies, sports, and restaurants. ci4
   1. ☐ Never
   2. ☐ 1-4 times
   3. ☐ 5 or more times

4: Visiting friends or relatives ci5
   1. ☐ Never
   2. ☐ 1-4 times
   3. ☐ 5 or more times

88 / 99 Declined to answer/Refused
99. ☐ Unknown
5: When you participate in leisure activities do you usually do this alone or with others? ci6
   1. □ Mostly alone
   2. □ Mostly with friends who have burn injuries
   3. □ Mostly with family members
   4. □ Mostly with friends who do not have burn injuries
   5. □ With a combination of family and friends

6: Do you have a best friend with whom you confide? ci7
   1. □ Yes
   2. □ No

CIQ Total Score: ciqsic

**Satisfaction with Life:**

Here are 5 statements with which you may agree or disagree. Using a scale where 1 represents you strongly disagree and 7 represents that you strongly agree, indicate your agreement with each item. Please be open and honest in your response.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree =1</th>
<th>Disagree =2</th>
<th>Slightly disagree=3</th>
<th>Neither agree nor disagree =4</th>
<th>Slightly agree=5</th>
<th>Agree =6</th>
<th>Strongly agree=7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In most ways my life is close to ideal: s11</td>
<td>□</td>
<td>□</td>
<td></td>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. The conditions of my life are excellent: s12</td>
<td>□</td>
<td>□</td>
<td></td>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. I am satisfied with my life s13</td>
<td>□</td>
<td>□</td>
<td></td>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. So far, I have gotten the important things I want in life s14</td>
<td>□</td>
<td>□</td>
<td></td>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. If I could live my life over again I would change almost nothing: s15</td>
<td>□</td>
<td>□</td>
<td></td>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Satisfaction with Life Total Score: swlscore

**PTGI:**

Next are some questions about ways people sometimes change after difficult events. Indicate for each of the next statements the degree to which this change occurred in your life as a result of your burn injury, using these response categories:

0 = I did not experience this change as a result of my burn injury
1 = I experienced this change to a very small degree as a result of my burn injury
2 = I experienced this change to a small degree as a result of my burn injury
3 = I experienced this change to a moderate degree as a result of my burn injury

88 / 99

Declined to answer/Refused

Unknown
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

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>code</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I changed my priorities about what is important in life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. I have a greater appreciation for the value of my own life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. I am able to do better things with my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. I have a better understanding of spiritual matters</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>5. I have a greater sense of closeness with others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>6. I established a new path for my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>7. I know better that I can handle difficulties.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>8. I have a stronger religious faith.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>9. I’ve discovered that I’m stronger than I thought I was.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>10. I learned a great deal about how wonderful people are.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

Post Traumatic Growth Inventory Total Score: ptgitot

DEMOGRAPHICS:

Finally I have some general questions about you.

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

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

2. What is your current height? (feet/inches) (code 9999 for unknown) wtfu
   Added to adult data collection in 2015
3. Where are you currently living? (Choose only one) resdencfu
   1. □ House
   2. □ Apartment
   3. □ Mobile home
   4. □ Institution
   5. □ Homeless
   6. □ Other

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

5. Who are you currently living with? (Choose all that apply)
   Interviewer instructions: Probe if needed to make sure that all people participant is living with are accounted
   for in their answer.
   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

   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

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)

8. In the past year, 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”)
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
Code: _____ occodefup

Interviewer instructions: Ask this as an open-ended question. Fill out the blank with the occupation the participant states and then the code, found below.
1 - Executive, Administrative, And Managerial; 2 - Professional Specialty; 3 - Technicians And Related Support; 4 - Sales; 5 - Administrative Support Including Clerical; 6 - Private Household; 7 - Protective Service; 8 - Service, Except Protective And Household; 9 - Farming, Forestry, And Fishing; 10 - Precision Production, Craft, And Repair; 11 - Machine Operators, Assemblers, And Inspectors; 12 - Transportation And Material Moving; 13 - Handlers, Equipment Cleaners, Helpers, And Laborers; 14 - Military Occupations; 77 – Not Applicable; 88 – Declined to Answer/Refused; 99 – Unknown

10. What is your current employment status? employ_fup
1. □ Working (Interviewer instructions: continue with next question)
2. □ Not working (looking for work)
3. □ Not working (not looking for work)
4. □ Homemaker/caregiver
5. □ Volunteer
6. □ Retired
88. □ Declined to answer/Refused
99. □ Unknown

Old variable was named “employfu”.

Wording changed with shift to new forms in 2015 from “current employment status” to “what is your current employment status?” Response options changed from one category, “not working”, to two categories, “not working (looking for work)” and “not working (not looking for work”). The response category 8, “N/A, 0-4 age group” removed due to shift to separation of pediatric forms. The use of the code for 2, “not working”, is no
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

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: returndate

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

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)
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.

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)

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
10. □ 10 years
11. □ 11 or 12 years; no diploma
12. □ High school diploma
13. □ Work towards Associate’s degree
14. □ Associate’s degree
15. □ Work towards Bachelor’s degree
16. □ Bachelor’s degree
17. □ Work towards Master’s degree
18. □ Master’s degree
19. □ Work towards doctorate level degree
20. □ Doctoral level degree
66. □ Other

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

18. Did you earn a GED instead of graduating from high school? **gedfup**
   1. □ No
   2. □ Yes
   77. □ Not applicable (high school diploma or attended college)

19. Are you currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) **disincfup**
   1. □ I am not receiving disability income (**Interviewer Instructions:** skip to #21 on page 13, if the participant is not receiving disability income)
   2. □ Social Security Disability
   3. □ Private long term insurance disability income
   4. □ Supplemental security income (SSI)
   5. □ Worker’s compensation
   6. □ Other __________

**Interviewer Instructions:** If the participant is receiving disability income, continue with #20

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

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

22. Do you currently have any psychological issues, such as depression or anxiety? **pyschisfup**
   1. □ Yes
   2. □ No
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)

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 Codebook Form II: Follow-up

New MSID: ________

**Please answer each question as it relates to your current health:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Skipped/Refused</th>
<th>Don’t know/Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hearing loss? (hloss)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Change in voice? (voice)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Vision problems not corrected by glasses or contact lenses? (vision)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Eyelid problems? (eyelid)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Excessive tearing of the eyes? (tear)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Difficulty with memory? (memory)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Difficulty with thought processing? (thought)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Numbness, pins and needles or burning sensations in your burn scar? (numbsc)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Numbness, pins and needles or burning sensations in your hands? (numbh)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Numbness, pins and needles or burning sensations in your feet? (numbf)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Trouble with your balance? (tbalan)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Varicose veins? (varvein)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Code</td>
<td>Yes</td>
<td>No</td>
<td>Skipped/Refused</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------</td>
<td>-----</td>
<td>-----</td>
<td>-----------------</td>
</tr>
<tr>
<td>13. Swollen feet or legs?</td>
<td>swfleg</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Swollen hands or arms?</td>
<td>swharm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Difficulty breathing when doing your regular daily activities?</td>
<td>difbrerg</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Difficulty breathing when exercising?</td>
<td>difbreex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Skin cancer?</td>
<td>skincanc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Joint pain?</td>
<td>jpain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Have you been pregnant or fathered a child since your last interview?</td>
<td>preg_fath</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Blood clots in legs or lungs?</td>
<td>bcleglung</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Cold intolerance?</td>
<td>cintol</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Excessive sweating?</td>
<td>exsweat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Difficulty in hot environments?</td>
<td>difhot</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11.</td>
<td>med11</td>
</tr>
<tr>
<td>12.</td>
<td>med12</td>
</tr>
</tbody>
</table>
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:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
</table>

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.

<table>
<thead>
<tr>
<th>Do you have problems…</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing? chcself1, chcself1a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Hearing? chcself2, chcself2a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Learning and understanding? chcself3, chcself1a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcself4, chcself4a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Controlling emotions or behavior? chcself5, chcself5a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. with Seizures or epilepsy? chcself6, chcself6a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. with Teeth and gums? chcself8, chcself8a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. with Type 1 or Type 2 diabetes? chcself10, chcself10a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. with Growth? chcself11, chcself11a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. Sleeping? chcself12, chcself12a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13. with Repeated infections? chcself13, chcself13a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14. with Breathing (eg asthma)? chcself14, chcself14a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16. with other Skin problems (eg eczema)? chcself16, chcself16a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17. with the Heart (such as a birth defect)? chcself17, chcself17a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
18. with Pain? chcself18, chcself18a [ ] Yes=1 [ ] No=0

19. Does you have any other health problems? chcself19 [ ] Yes [ ] No
If yes, specify problem: ________________chcself19ot (text field)

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

2. In the past 12 months, did you take medication for being, worried, tense, or anxious? wmed_pre
   1. [ ] Yes
   2. [ ] No

3. In the past 12 months, did you take medication for being sad, empty, or depressed? smed_pre
   1. [ ] Yes
   2. [ ] No

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...

<table>
<thead>
<tr>
<th>In the four weeks before my burn…</th>
<th>Strongly Disagree=1</th>
<th>Disagree=2</th>
<th>Neither Agree nor Disagree=3</th>
<th>Agree=4</th>
<th>Strongly Agree=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My life was going well. pa066pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My life was just right pa067pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I had a good life pa070pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I had what I wanted in life pa071pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NIH General Life Satisfaction Total Score Pre-Injury: tbglstscore_13_17_pre

CIO Pre-Burn:
The next questions I have are about activities you might have participated in before your burn injury.

During the 4 weeks before your burn:
1. Did you take responsibility for personal grooming when asked? cip2_pre
   1. □ Often 88. □ Declined to answer/Refused
   2. □ Sometimes 99. □ Unknown
   3. □ Never

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

2: Shopping ci3_pre
   1. □ Never 88. □ Declined to answer/Refused
   2. □ 1-4 times 99. □ Unknown
   3. □ 5 or more times

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

4: Visiting friends or relatives ci5_pre
   1. □ Never 88. □ Declined to answer/Refused
   2. □ 1-4 times 99. □ Unknown
   3. □ 5 or more times

During the 4 weeks before your burn:

5: When you participated in leisure activities did you usually do this alone or with others? ci6_pre
   1. □ Mostly alone 88. □ Declined to answer/Refused
   2. □ Mostly with friends who have burn injuries (N/A for Form I) 99. □ Unknown
   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 88. □ Declined to answer/Refused
   2. □ No 99. □ Unknown

Pre-Injury Demographics

1. Before your burn injury, where were you living? (Choose only one) resdenc
   1. □ House 88. □ Declined to answer/Refused
   2. □ Apartment 99. □ Unknown
   3. □ Mobile home
   4. □ Institution
   5. □ Homeless
   6. □ Other

Wording of variable changed with move to new forms in 2015 from “Residence at time of burn injury” to “before your burn injury, where were you living?”

2. What was your zip code at the time of your burn injury? __ __ __ __ __ zip_pre
(Code 99999 for unknown, code 00000 for Mexico)

Added to data collection forms in 2015.

3. Who were you living with before your burn injury? (Choose all that apply)
   4. Parent or step-parent livinga_4
   5. Other relative (siblings, grandparents) livinga_5
   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
   3. In school/below age appropriate
   88. □ Declined to answer/Refused
   99. □ Unknown

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

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

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

7. Before the burn, did you have any psychological issues, such as depression or anxiety? psychis
   1. Yes
   2. No
   88. □ Declined to answer/Refused
   99. □ Unknown

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

Demographics
This is the last section of the survey.

Interviewer Instructions: Use medical record for #1 and #2. Skip these questions unless self-report is best source, and record answer onto the Form I Medical Record Abstraction Form along with source of data. If disposition (#2, below) is not clear on Medical Record, clarify with participant.

1. What were the circumstances of your burn injury? (Choose only one)  
   - Non-intentional employment related
   - Non-intentional non-work related (Interviewer Instructions: choose this category if employment and/or recreation do not apply)
   - Non-intentional recreation
   - Non-intentional non-specified (Interviewer Instructions: choose this category if there is no information on circumstances other than non-intentional)
   - Suspected assault-domestic
   - Suspected assault-non domestic
   - Suspected self-inflicted/suicide
   - Suspected arson
   - Declined to answer/Refused
   - 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)  
   - Died, burn related
   - AMA/Unable to complete treatment
   - Patient home
   - Other home (includes hospital owned apartments)
   - Extended care facility
   - Other rehab facility (not model system)
   - Institution
   - Drug/alcohol treatment center
   - Shelter
   - Street
   - Died, non-burn related
   - Other
   - Declined to answer/Refused
   - 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) ethnicity
   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
   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
   2. Apartment
   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
   7. Guardian livhisdis ___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”.

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
   2. 2 years
   3. 3 years
   4. 4 years
   5. 5 years
   6. 6 years
   7. 7 years
   8. 8 years
   88. Declined to answer/Refused
   99. Unknown
9. ☐ 9 years
10. ☐ 10 years
11. ☐ 11 or 12 years; no diploma
12. ☐ High school diploma
66. ☐ Other

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

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 \textit{proxydis$_1$} \textit{proxydis$_77$, not applicable (not proxy)}
2. [ ] Father or stepfather \textit{proxydis$_2$}
3. [ ] Guardian \textit{proxydis$_3$}
4. [ ] Other \textit{proxydis$_4$}

1. What is the method of administration of this form? \textit{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? \textit{language}
   1. [ ] English
   2. [ ] Spanish
   3. [ ] Other

3. Checklist of forms: mark when each is complete \textit{status}
   1. [ ] Patient Status Form \textit{status$_1$}; 0=not checked; 1=checked
   2. [ ] Medical Record Abstraction Form \textit{status$_2$}; 0=not checked; 1=checked
   3. [ ] Review of Systems Checklist Form \textit{status$_3$}; 0=not checked; 1=checked
   4. [ ] Form I \textit{status$_4$}; 0=not checked; 1=checked

\textbf{Interviewer Instructions:} Instructions to the interviewer appear throughout the survey in \textit{Times New Roman} font and italics, and scripts to read aloud to the participants appear in \textit{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.

\textbf{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:

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
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<td>No=0</td>
<td></td>
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<td></td>
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</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Does your child have problems...</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<td>1. Seeing? chcprox1, chcprox1a</td>
<td>Yes=1</td>
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<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td>Yes=1</td>
<td></td>
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<tr>
<td>3. Learning and understanding? chcprox3, chcprox3a</td>
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<tr>
<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a</td>
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<tr>
<td>5. Controlling emotions or behavior? chcprox5, chcprox5a</td>
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<tr>
<td>6. with Seizures or epilepsy? chcprox6, chcprox6a</td>
<td>Yes=1</td>
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<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>Yes=1</td>
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<tr>
<td>8. with Teeth and gums? chcprox8, chcprox8a</td>
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<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a</td>
<td>Yes=1</td>
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<tr>
<td>10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a</td>
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<td>11. with Growth? chcprox11, chcprox11a</td>
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<tr>
<td>12. Sleeping? chcprox12, chcprox12a</td>
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<td>13. with Repeated infections? chcprox13, chcprox13a</td>
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<tr>
<td>14. with Breathing (eg asthma)? chcprox14, chcprox14a</td>
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<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a</td>
<td>Yes=1</td>
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<tr>
<td>16. with other Skin problems (eg eczema)? chcprox16, chcprox16a</td>
<td>Yes=1</td>
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</tbody>
</table>
Variable names and information appear in red

17. with the Heart (such as a birth defect)? chcprox17, chcprox17a
   Yes=1 □ □ □ □ □ □ □ □ No=0 □ □ □ □ □ □ □ □

18. with Pain? chcprox18, chcprox18a
   Yes=1 □ □ □ □ □ □ □ □ No=0 □ □ □ □ □ □ □ □

19. Does your child have any other health problems? chcprox19 □ Yes □ No
   If yes, specify problem: ___chcprox19ot (text field) _____________

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

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

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

These questions added with new forms in December 2015.

Pre-Injury Demographics

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

2. What was your child’s zip code at the time of his/her burn injury? ___ ___ ___ ___ zipprx_pre
   (Code 99999 for unknown, code 00000 for Mexico)

3. Who was your child living with before his/her burn injury? (Choose all that apply)
   4. □ Parent or step-parent livingaprx___4
   5. □ Other relative (siblings, grandparents) livingaprx___5
   6. □ Others, not part of family livingaprx___6
   7. □ Guardian livingaprx___7 livingaprx_88, 88. □ Declined to answer/Refused
   livingaprx_99, 99. □ Unknown
Variable names and information appear in red

BMS Pediatric Parent Proxy 0-7 Codebook Form I
NewMSID_________

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

   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

6. Before the burn, did your child have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? physprobprepx
   1. □ Yes 2. □ No

7. Before the burn, did your child have any psychological issues, such as depression or anxiety? psychisprx
   1. □ Yes 2. □ No

8. Did your child receive psychological therapy or counseling in the last 12 months? psychtrprx
   1. □ Yes 2. □ No

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) ethnicity

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

Stored in Patient Status Form—this variable appears on the Form I in case it has not yet been gathered.
2. After your child’s hospital discharge, where will he/she be living? (Choose only one)  
   dislivsitprx
   1. House
   2. Apartment
   3. Mobile home
   4. Institution
   5. Homeless
   6. Other

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)  
   livhisdisprx___4
   4. Parent or step-parent
   5. Other relative (siblings, grandparents)
   6. Others, not part of family
   7. Guardian

The previous variable “livhdis” 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 has your child completed? educdisprx
   Interviewer instructions: Ask the question as open-ended, and then mark the appropriate response below.
   0. Preschool completed
   1. 1 year or less
   2. 2 years
   3. 3 years
   77. Not applicable (child is too young for school)

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)?  
   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)

   How many people are in your household? __________ numhspreprx
   (Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)
6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) 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 88. □ Declined to answer/Refused 99. □ Unknown
   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)

*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:

<table>
<thead>
<tr>
<th>In the four weeks before my child’s burn injury…</th>
<th>1= Strongly disagree</th>
<th>2= Disagree</th>
<th>3= Neither agree nor disagree</th>
<th>4= Agree</th>
<th>5= Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child's life was going well.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. My child's life was just right.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>papxy067pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>3. My child had a good life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>papxy070pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. My child had what he/she wanted in life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is there anything else you would like to tell us?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

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

Indicate time survey ended: ____________
Today’s Date: ___ ___ / ___ ___ / ___ ___

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

Indicate time survey started: ____________

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

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

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

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

3. Checklist of forms: mark when each is complete status
   1. [ ] Patient Status Form status__1; 0=not checked; 1=checked
   2. [ ] Medical Record Abstraction Form status__2; 0=not checked; 1=checked
   3. [ ] Review of Systems Checklist Form status__3; 0=not checked; 1=checked
   4. [ ] Form I status__4; 0=not checked; 1=checked

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant. If a participant doesn’t want to answer any item or doesn’t know the answer, circle “88” (Declined to Answer/Refused) or “99” (Unknown) next to that item. Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview.

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

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

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

**Answer Key:**

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

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

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

Let’s get started. The first section is about your child’s current health.
**Child Health Conditions**

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

Responses for this question are:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not at all</td>
<td>To a very small extent</td>
<td>To a small extent</td>
<td>To a moderate extent</td>
<td>To a fairly great extent</td>
<td>To a great extent</td>
<td>To a very great extent</td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Does your child have problems…</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing? chcprox1, chcprox1a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Learning and understanding? chcprox3, chcprox3a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Controlling emotions or behavior? chcprox5, chcprox5a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. with Seizures or epilepsy? chcprox6, chcprox6a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. with Teeth and gums? chcprox8, chcprox8a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. with Growth? chcprox11, chcprox11a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. Sleeping? chcprox12, chcprox12a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13. with Repeated infections? chcprox13, chcprox13a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14. with Breathing (eg asthma)? chcprox14, chcprox14a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16. with other Skin problems (eg eczema)? chcprox16, chcprox16a</td>
<td>Yes=1, No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17. with the Heart (such as a birth defect)? chcprox17</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
18. with Pain? chcprox18, chcprox18a
   Yes = 1
   No = 0

19. Does your child have any other health problems? chcprox19
   Yes
   No
   If yes, specify problem: ___ chcprox19ot (text field)___

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

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

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

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

NIH Toolbox General Life Satisfaction
Indicate how much you agree or disagree:
**Pre-Injury Demographics**

1. Before your child’s burn injury, where was he/she living? (Choose only one) resdencprx
   - House
   - Apartment
   - Mobile home
   - Institution
   - Homeless
   - Other

2. What was your child’s zip code at the time of his/her burn injury? __ __ __ __ zipprx_pre
   
   (Code 99999 for unknown, code 00000 for Mexico)

3. Who was your child living with before his/her burn injury? (Choose all that apply)
   - Parent or step-parent livingaprx__4
   - Other relative (siblings, grandparents) livingaprx__5
   - Others, not part of family livingaprx__6
   - Guardian livingaprx__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. 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
   - In school/age or above age appropriate
   - Not in school
   - 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

6. Before the burn, did your child have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? physprobprepx
   1. [ ] Yes 2. [ ] No

7. Before the burn, did your child have any psychological issues, such as depression or anxiety? psychisprx
   1. [ ] Yes 2. [ ] No

8. Did your child receive psychological therapy or counseling in the last 12 months? psychtrprx
   1. [ ] Yes 2. [ ] No

**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
1. What is your child’s race and/or ethnicity? (Choose only one) 
   - [ ] White, non-Hispanic (including Middle Eastern and Indian)
   - [ ] Black, non-Hispanic
   - [ ] Hispanic
   - [ ] Pacific Islander
   - [ ] Asian
   - [ ] Native American
   - [ ] Multi-Racial
   - [ ] Other

2. After your child’s hospital discharge, where will he/she be living? (Choose only one)
   - [ ] House
   - [ ] Apartment
   - [ ] Mobile home
   - [ ] Institution
   - [ ] Homeless
   - [ ] Other

3. Who will your child be living with after hospital discharge? (Choose all that apply)
   - [ ] Parent or step-parent
   - [ ] Other relative (siblings, grandparents)
   - [ ] Others, not part of family
   - [ ] Guardian

4. How many years of education has your child completed?
   - [ ] Declined to answer/Refused
   - [ ] Unknown

Interviewer instructions: Ask the question as open-ended.
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 ________

(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.”

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)

How many people are in your household? ________

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

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

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 ______________

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)

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)

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
   2. □ Sometimes
   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
   2. □ 1-4 times
   3. □ 5 or more times

3: Leisure activities such as movies, sports, and restaurants. ci4prx_pre
   1. □ Never
   2. □ 1-4 times
   3. □ 5 or more times

4: Visiting friends or relatives ci5prx_pre
   88. □ Declined to answer/Refused
   99. □ Unknown
During the 4 weeks before your child’s burn:
5: When your child participated in leisure activities did he/she usually do this alone or with others?  

<table>
<thead>
<tr>
<th></th>
<th>Mostly alone</th>
<th>Mostly with family members</th>
<th>Mostly with friends</th>
<th>With a combination of family and friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>□</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>□</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>□</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>□</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>□</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

**BMS Pediatric 8-12 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.

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/withdraw
   9. Incarcerated
   10. Still in hospital (not discharged yet)
   11. Unable to travel for assessment

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

Option 14 added with new forms in 2015
Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant. Have the updated Patient Status form with you to help with the interview.

If a participant doesn’t want to answer any item or doesn’t know the answer, circle “88” (Declined to Answer/Refused) or “99” (Unknown) next to that item.

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

Introduction script:
Hi my name is _____ and I am calling from _____ to ask you some questions about how you have been doing (since your injury)… or (since we last spoke with you on (last follow-up date)).

Thank you for continuing to participate in our study of children with burn injuries. Like our previous interviews, I’ll be asking questions about your burn injury and other questions about you and people around you. Your answers will help us understand the experiences of kids with burn injury. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential.

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

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

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

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

Let’s get started.
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Pediatric 8-12 Codebook Form II**
NewMSID_________

### Body Image

The following questions ask about your appearance:

<table>
<thead>
<tr>
<th>Question</th>
<th>Definitely true=1</th>
<th>Mostly true=2</th>
<th>Not sure=3</th>
<th>Mostly false=4</th>
<th>Definitely false=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel that the burn is unattractive to others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bodyim_1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I think people would not want to touch me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bodyim_2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I feel unsure of myself among strangers.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bodyim_3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Changes in my appearance have interfered with my relationships.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bodyim_4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 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.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all or only at one time=0</th>
<th>Once a week or less/once in a while=1</th>
<th>2 to 4 times a week/half the time=2</th>
<th>5 or more times a week/almost always=3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having upsetting thoughts or images about your burn injury that came into your head when you didn’t want them to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Having bad dreams or nightmares</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Acting or feeling as if your burn injury was happening again</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(hearing something or seeing a picture about it and feeling as if I am there again)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Trying not to think about, talk about, or have feelings about your burn injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Trying to avoid activities, people, or places that remind you of your burn injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Not being able to remember an important part of your burn injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_8</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Having much less interest or doing things you used to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>cpss_9</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Not feeling close to people around you</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Response Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy)</td>
<td>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</td>
</tr>
<tr>
<td>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)</td>
<td>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</td>
</tr>
<tr>
<td>13. Having trouble falling or staying asleep</td>
<td>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</td>
</tr>
<tr>
<td>14. Feeling irritable or having fits of anger</td>
<td>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</td>
</tr>
<tr>
<td>15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class)</td>
<td>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</td>
</tr>
<tr>
<td>16. Being overly careful (for example, checking to see who is around you and what is around you)</td>
<td>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</td>
</tr>
<tr>
<td>17. Being jumpy or easily startled (for example, when someone walks up behind you)</td>
<td>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</td>
</tr>
</tbody>
</table>

**CPSS Total Score Variable: cpss_tot_score**

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

<table>
<thead>
<tr>
<th>In the past 7 days...</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt mad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I felt fed up</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I was so angry I felt like throwing something</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I was so angry I felt like yelling at somebody</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. When I got mad, I stayed mad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PROMIS Anger Total Score Pediatric: angtscore_ped**
**BMS Pediatric 8-12 Codebook Form II**

**NewMSID**

---

**PROMIS 25**

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

**Physical function mobility**

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

**Anxiety**

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt like something awful might happen pr2220r2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. I felt nervous pr713r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. I felt worried pr5044r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. I worried when I was at home pr3459br1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**Depressive Symptoms**

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt everything in my life went wrong pr5041r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. I felt lonely pr711r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. I felt sad pr228r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. It was hard for me to have fun pr3952ar2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**Fatigue**

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Pediatric 8-12 Codebook Form II**

**NewMSID**

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Response Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Being tired made it hard for me to keep up with my schoolwork</td>
<td>pr4239r2</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. I got tired easily</td>
<td>pr2876r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. I was too tired to do sports or exercise</td>
<td>pr4241r2</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. I was too tired to enjoy the things I like to do</td>
<td>pr4196r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

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

**Peer relationships**

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Response Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt accepted by other kids my age</td>
<td>pr5018r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. I was able to count on my friends</td>
<td>pr5058r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. My friends and I helped each other out</td>
<td>pr5055r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. Other kids wanted to be my friend</td>
<td>pr233r2</td>
<td>0</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

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

**Pain interference**

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Response Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had trouble sleeping when I had pain</td>
<td>pr3793r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. It was hard for me to pay attention when I had pain</td>
<td>pr9004</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. It was hard for me to run when I had pain</td>
<td>pr2045r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. It was hard for me to walk one block when I had pain</td>
<td>pr2049r1</td>
<td>0</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Response Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 7 days...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pain intensity</strong></td>
<td>pr9033r1</td>
<td></td>
<td>88.</td>
</tr>
<tr>
<td>How bad was your pain on average?</td>
<td>pr9033r1</td>
<td></td>
<td>99.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Response</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td></td>
</tr>
<tr>
<td>□</td>
<td></td>
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<tr>
<td>□</td>
<td></td>
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<td>□</td>
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<tr>
<td>□</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Response Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicate how much you agree or disagree...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Disagree=1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree=2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither Agree nor</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree=4</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree=5</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-No pain</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-Worst pain you can think of</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-Worst pain you can think of</td>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Pediatric 8-12 Codebook Form II**
NewMSID________

<table>
<thead>
<tr>
<th>Question</th>
<th>0=No change</th>
<th>1=A little</th>
<th>2=Some</th>
<th>3=A lot</th>
<th>99=Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I learned how nice and helpful some people can be.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. I can now handle big problems better than I used to.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. I know what is important to me better than I used to.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. I understand how God works better than I used to.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. I feel closer to other people (friends or family) than I used to.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. I appreciate (enjoy) each day more than I used to.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**NIH General Life Satisfaction Self-report T-Score: tglstscore8_12_ped**

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

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had trouble sleeping when I was itching</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. I felt angry when I was itching</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. I had trouble doing schoolwork when I was itching</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. It was hard for me to pay attention when I was itching</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. It was hard for me to have fun when I was itching</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Post-Traumatic Growth Inventory Total Score: ptgictot

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

PTGI Child Total Score Variable: ptgictot

Is there anything else you would like to tell us?

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

Indicate time survey ended: __________
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
   9. □ Incarcerated
   10. □ Still in hospital (not discharged yet)
   11. □ Unable to travel for assessment Option 14 added with new forms in 2015

*Interviewer Instructions: Update date and cause of death on Patient Status Form*
**Interviewer Instructions:** Instructions to the interviewer appear throughout the survey in *Times New Roman* font and italics, and scripts to read aloud to the participants appear in *Arial* font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant. Have the updated *Patient Status form* with you to help with the interview.

If a participant doesn’t want to answer any item or doesn’t know the answer, circle “88” (Declined to Answer/Refused) or “99” (Unknown) next to that item.

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

---

**Introduction script:**
Hi my name is ___ and I am calling from _____ to ask you some questions about how you have been doing (since your injury)... or (since we last spoke with you on (last follow-up date)).

Thank you for continuing to participate in our study of 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? *psychther*
   - Yes
   - 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.

2. Since your last interview, have you spoken with other burn survivors to get support for problems related to your burn injury? *peersup*
   - Yes
   - No

   Added in 2015

3. Since the last interview, have you received any of the following services at home or outpatient? *(Choose all that apply)*
   - No services
   - Occupational therapy
   - Physical therapy
   - Speech language pathology
   - Social work
   - Psychological services
   - Vocational services

   *Interviewer Instructions*: skip to #10, surgery item, on page 6

   0 = not checked
   1 = checked

   Added in 2015

   *Interviewer Instructions*: if participant indicates that services were received but that those services were not occupational and/or physical therapy, skip to #10, surgery item, on page 4.

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

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

   Added in 2015

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

5. Burn center?
   - Yes
   - No

   77. Not applicable (no OT/PT received)

   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)

   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)

   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)

   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]? numsurg
   __________ (code 77 for N/A—no surgery and code 99 for unknown number of surgeries)

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

   src_numsurg (77—Not applicable (no surgeries))

10. Which burn related surgeries have you had since your last interview?
   (Choose all that apply)

   1. ☐ Surgery for open wounds surgtype_1
   2. ☐ Surgery for joint contractures surgtype_2
   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 amputfu1__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) □ checked; 1=checked  
Notes: New variable added with new Forms in 2015  
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:

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all</th>
<th>2 To a very small extent</th>
<th>3 To a small extent</th>
<th>4 To a moderate extent</th>
<th>5 To a fairly great extent</th>
<th>6 To a great extent</th>
<th>7 To a very great extent</th>
</tr>
</thead>
</table>

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.

<table>
<thead>
<tr>
<th>Do you have problems…</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>28x99</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing? chcself1, chcself1a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. Hearing? chcself2, chcself2a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. Learning and understanding? chcself3, chcself1a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcself4, chcself4a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>5. Controlling emotions or behavior? chcself5, chcself5a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>6. with Seizures or epilepsy? chcself6, chcself6a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>8. with Teeth and gums? chcself8, chcself8a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcself9, chcself9a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>10. with Type 1 or Type 2 diabetes? chcself10, chcself10a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>11. with Growth? chcself11, chcself11a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>12. Sleeping? chcself12, chcself12a</td>
<td>Yes=1 No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>13. with Repeated infections? chcself13,</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>
Variable names appear in red.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. with Breathing (eg asthma)? chcself14, chcself14a</td>
<td>Yes=1</td>
<td>No=0</td>
</tr>
<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a</td>
<td>Yes=1</td>
<td>No=0</td>
</tr>
<tr>
<td>16. with other Skin problems (eg eczema)? chcself16, chcself16a</td>
<td>Yes=1</td>
<td>No=0</td>
</tr>
<tr>
<td>17. with the Heart (such as a birth defect)? chcself17, chcself17a</td>
<td>Yes=1</td>
<td>No=0</td>
</tr>
<tr>
<td>18. with Pain? chcself18, chcself18a</td>
<td>Yes=1</td>
<td>No=0</td>
</tr>
<tr>
<td>19. Do you have any other health problems? chcself19</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>If yes, specify problem: ______________ chcsel19ot (text field)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain Medication**

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

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

2. In the past month did you take prescription medication for itch on a regular basis? imed
   1. Yes
   2. No

3. In the past 12 months, did you take medication for being, worried, tense, or anxious? wmed
   1. Yes
   2. No

4. In the past 12 months, did you take medication for being sad, empty, or depressed? smed
   1. Yes
   2. No

**Body Image**

The following questions ask about your appearance:

<table>
<thead>
<tr>
<th>Question</th>
<th>Definitely true=1</th>
<th>Mostly true=2</th>
<th>Not sure=3</th>
<th>Mostly false=4</th>
<th>Definitely false=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel that the burn is unattractive to others. bodyim_1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I think people would not want to touch me. bodyim_2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I feel unsure of myself among strangers. bodyim_3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Changes in my appearance have interfered with my relationships.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**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.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all or only at one time</th>
<th>Once a week or less/once in a while</th>
<th>2 to 4 times a week/half the time</th>
<th>5 or more times a week/almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having upsetting thoughts or images about your burn injury that came into your head when you didn’t want them to</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Having bad dreams or nightmares</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>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)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>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)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Trying not to think about, talk about, or have feelings about your burn injury</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Trying to avoid activities, people, or places that remind you of your burn injury</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. Not being able to remember an important part of your burn injury</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. Having much less interest or doing things you used to do</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. Not feeling close to people around you</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>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)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13. Having trouble falling or staying asleep</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14. Feeling irritable or having fits of anger</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16. Being overly careful (for example, checking to see who is</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
### PROMIS Anger

**CPSS Total Score Variable: cpss_tot_score**

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

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt mad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr206r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr714r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I felt fed up</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr5045r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I was so angry I felt like throwing something</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr2319ar1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I was so angry I felt like yelling at somebody</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr2581r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. When I got mad, I stayed mad proang_6 (not administered on spanish forms)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PROMIS Anger Total Score Pediatric: angtscore_ped**

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

**Physical function mobility**

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

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

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt like something awful might happen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr2220r2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt nervous</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr713r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I felt worried</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>pr5044r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Depressive Symptoms

**In the past 7 days…**

<table>
<thead>
<tr>
<th></th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
</table>
| 1. I felt everything in my life went wrong | | | | | | pr5041r1
| 2. I felt lonely | | | | | | pr711r1
| 3. I felt sad | | | | | | pr228r1
| 4. It was hard for me to have fun | | | | | | pr3952ar2

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

### Fatigue

**In the past 7 days…**

<table>
<thead>
<tr>
<th></th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
</table>
| 1. Being tired made it hard for me to keep up with my schoolwork | | | | | | pr4239ar2
| 2. I got tired easily | | | | | | pr2876r1
| 3. I was too tired to do sports or exercise | | | | | | pr4241r2
| 4. I was too tired to enjoy the things I like to do | | | | | | pr4196r1

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

### Peer relationships

**In the past 7 days…**

<table>
<thead>
<tr>
<th></th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
</table>
| 1. I felt accepted by other kids my age | | | | | | pr5018r1
| 2. I was able to count on my friends | | | | | | pr5058r1
| 3. My friends and I helped each other out | | | | | | pr5055r1
| 4. Other kids wanted to be my friend | | | | | | pr233r2

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

### Pain Interference

**In the past 7 days…**

<table>
<thead>
<tr>
<th></th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
</table>
| 1. I had trouble sleeping when I had pain | | | | | | pr3793r1

**PROMIS Fatigue T-Score Variable: fattscore_ped**
2. It was hard for me to pay attention when I had pain

3. It was hard for me to run when I had pain

4. It was hard for me to walk one block when I had pain

Pain Intensity

In the past 7 days…

How bad was your pain on average?

<p>| | | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0-No pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10-Worst pain you can think of</td>
</tr>
</tbody>
</table>

NIH TB General Life Satisfaction CAT Ages 13-17

Indicate how much you agree or disagree…

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree=1</th>
<th>Disagree=2</th>
<th>Neither Agree nor Disagree=3</th>
<th>Agree=4</th>
<th>Strongly Agree=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My life is going well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My life is just right</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I have a good life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I have what I want in life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

GLS Total Score Variable: tbglstscore13_17_ped

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

In the past 7 days…

<table>
<thead>
<tr>
<th></th>
<th>0=Never</th>
<th>1=Almost Never</th>
<th>2=Sometimes</th>
<th>3=Often</th>
<th>4=Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had trouble sleeping when I was itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt angry when I was itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I had trouble doing schoolwork when I was itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. It was hard for me to pay attention when I was itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. It was hard for me to have fun when I was itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Question</th>
<th>0=No change</th>
<th>1=A little</th>
<th>2=Some</th>
<th>3=A lot</th>
<th>99=Don’t</th>
</tr>
</thead>
</table>

---

---
### PTGI Child Version Total Score Variable: ptgictot

**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

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th>know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I learned how nice and helpful some people can be.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I can now handle big problems better than I used to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I know what is important to me better than I used to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I understand how God works better than I used to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I feel closer to other people (friends or family) than I used to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I appreciate (enjoy) each day more than I used to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I now have a chance to do some things I couldn’t do before.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>My faith (belief) in God is stronger than it was before.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I have learned that I can deal with more things than I thought I could before.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I have new ideas about how I want things to be when I grow up.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. □ Other

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

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

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

   4. □ Parent or step-parent livingafu___4  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?: ____ / ____ / _______
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?)*)  edufcp

*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

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

1. □ I am not receiving disability income *(Interviewer Instructions: skip to #13, 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 ______________

*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)? phsyprobfup

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
Is there anything else you would like to tell us? ________________________________  
___________________________________________________________________________ 
___________________________________________________________________________ 

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

Indicate time survey ended: ____________
FT2. Today's Date: ____ __/____ __/____ ___  
(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: __________  

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

Who is filling out this questionnaire? (Select all that apply)  
1. [ ] Mother or stepmother proxy__1 proxy__77, not applicable (not proxy)  
2. [ ] Father or stepfather proxy__2  
3. [ ] Guardian proxy__3  
4. [ ] Other proxy__4  

1. Follow-up period  
   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.
**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?  
   - [ ] Yes  
   - [ ] 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?  
   - [ ] Yes  
   - [ ] No  
   - 77. [ ] Not applicable  
   - 99. [ ] Don’t know

3. Since the last interview, has your child received any of the following services at home or outpatient? *(Choose all that apply)*  
   - [ ] No services *(Interviewer Instructions: skip to #10, surgery item, on page 6)*  
   - [ ] Occupational therapy  
   - [ ] Physical therapy  
   - [ ] Speech language pathology  
   - [ ] Social work  
   - [ ] Psychological services  
   - [ ] Vocational services  
   
   0=not checked  
   1=checked  
   88. [ ] Declined to answer/Refused  
   88. [ ] Unknown  
   99. [ ] Unknown

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

Since your last interview, where did your child receive his/her outpatient occupational or physical burn therapy? ther_brn_ctrprx
5. This clinical burn center? 88. □ Declined to answer/Refused
   1. □ Yes
   2. □ No
   77. □ Not applicable (no OT/PT received)

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

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

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

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

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

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

   src_numsurgprx
13. Which burn related surgeries has your child had since your last interview?
   (Choose all that apply)
   1. [ ] Surgery for open wounds surgtypeprx___1
   2. [ ] Surgery for joint contractures surgtypeprx___2
   3. [ ] Surgery for scar management surgtypeprx___3
   4. [ ] Amputation surgtypeprx___4
   5. [ ] Other surgtypeprx___5 (if so, what? otsurgprx)
   7. [ ] Not applicable (no surgery) surgtypeprx___77

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

Amputations

1. Has your child had an upper extremity amputation due to burn injury since your last interview?
   (Choose all that apply) Interviewer Instructions: ask as open ended and then mark the correct response.
   1. [ ] No amputfu1prx___1; 0=not checked; 1=checked
   2. [ ] Yes, above elbow right amputfu1prx___2; 0=not checked; 1=checked
   3. [ ] Yes, above elbow left amputfu1prx___3; 0=not checked; 1=checked
   4. [ ] Yes, above elbow bilateral amputfu1prx___4; 0=not checked; 1=checked
   5. [ ] Yes, below elbow right amputfu1prx___5; 0=not checked; 1=checked
   6. [ ] Yes, below elbow left amputfu1prx___6; 0=not checked; 1=checked
   7. [ ] Yes, below elbow bilateral amputfu1prx___7; 0=not checked; 1=checked
   8. [ ] Yes, digits only right numudgtrfuprx (fill in # of digits) (Thumb amputated? thumbrfu __)
      1=Yes 2-No, 99=Unknown)
   9. [ ] Yes, digits only left numudgtrfuprx (fill in # of digits) (Thumb amputated? thumblfuprx __)
      1=Yes 2-No, 99=Unknown)
   10. [ ] Yes, digits only bilateral numudgtrfuprx (fill in # of digits) (Thumbs amputated? thumblfuprx __)
       1=Yes 2-No, 99=Unknown)

Notes:
New variable added with new Forms in 2015

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
**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:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>To a very small extent</td>
<td>To a small extent</td>
<td>To a moderate extent</td>
<td>To a fairly great extent</td>
<td>To a great extent</td>
<td>To a very great extent</td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Does your child have problems…</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing? chcprox1, chcprox1a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>No=0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td>Yes=1</td>
<td>☐</td>
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<tr>
<td></td>
<td>No=0</td>
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<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>3. Learning and understanding? chcprox3, chcprox3a</td>
<td>Yes=1</td>
<td>☐</td>
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<td></td>
<td>No=0</td>
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<tr>
<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
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<td>No=0</td>
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<tr>
<td>5. Controlling emotions or behavior? chcprox5, chcprox5a</td>
<td>Yes=1</td>
<td>☐</td>
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<tr>
<td>6. with Seizures or epilepsy? chcprox6, chcprox6a</td>
<td>Yes=1</td>
<td>☐</td>
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<td>No=0</td>
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<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>Yes=1</td>
<td>☐</td>
<td>☐</td>
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<td>No=0</td>
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<tr>
<td>8. with Teeth and gums? chcprox8, chcprox8a</td>
<td>Yes=1</td>
<td>☐</td>
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<td>No=0</td>
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<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a</td>
<td>Yes=1</td>
<td>☐</td>
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<tr>
<td>10. with Type 1 or Type 2 diabetes?</td>
<td>Yes=1</td>
<td>☐</td>
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</tbody>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Pediatric Proxy 0-7 Codebook Form II**

NewMSID____________

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>11. with Growth? chcprox11, chcprox11a</td>
<td>Yes=1</td>
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<td></td>
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<tr>
<td>12. Sleeping? chcprox12, chcprox12a</td>
<td>Yes=1</td>
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<td>13. with Repeated infections? chcprox13, chcprox13a</td>
<td>Yes=1</td>
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<td>14. with Breathing (eg asthma)? chcprox14, chcprox14a</td>
<td>Yes=1</td>
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<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a</td>
<td>Yes=1</td>
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<tr>
<td>16. with other Skin problems (eg eczema)? chcprox16, chcprox16a</td>
<td>Yes=1</td>
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<tr>
<td>17. with the Heart (such as a birth defect)? chcprox17, chcprox17a</td>
<td>Yes=1</td>
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<tr>
<td>18. with Pain? chcprox18, chcprox18a</td>
<td>Yes=1</td>
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</tbody>
</table>

19. Does your child have any other health problems? chcprox19  
   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.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0= Not At All</th>
<th>1= A little bit</th>
<th>2= Some -what</th>
<th>3= Quite a bit</th>
<th>4= Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pain bmspain</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Itching bmsitch</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

**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? pmedpxr
   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? imedpx
   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? wmedpx
   1. □ Yes  
   2. □ No  
   88. □ Declined to answer/Refused  
   99. □ Unknown
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

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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 livingafu___88
   5. ☐ Other relative (siblings, grandparents) livingafu___5 livingafu___99
   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 child’s current school status? aschoolfuprx
   1. ☐ In School *(Interviewer Instructions: Continue with #7 below if this is a 6, 12, or 24 month follow-up. Skip to #8 below if this is a 5, 10, or 15 year follow-up.)*
   2. ☐ Not in School *(Interviewer Instructions: Skip to #10 on the next page)*
   99. ☐ Unknown

*Interviewer Instructions: If in school and this is a 6, 12, or 24 month follow-up, ask…*

7. …is it the same program or a new program as compared with your last interview? *(Or, as compared with before his/her burn injury, if this is a 6 month follow-up).* aprogfuprx

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

   1. ☐ Same program full time 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 child is going to school. whynotfuprx
8. If your child isn’t going to school, why not?
   1. ☐ Burn related
   2. ☐ Other medical problems
   3. ☐ Emotional/social
   4. ☐ Legal/jail
   5. ☐ Substance abuse
   6. ☐ Personal choice
   7. ☐ Other
   77. ☐ Not applicable (going to school)

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) :____/_____/_______ retnrat

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)

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

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

*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)? 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)
Body Image

The following questions ask about this child’s appearance:

<table>
<thead>
<tr>
<th>Question</th>
<th>Definitely true=1</th>
<th>Mostly true=2</th>
<th>Not sure=3</th>
<th>Mostly false=4</th>
<th>Definitely false=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. This child feels that the burn is unattractive to others.</td>
<td></td>
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<tr>
<td>bodyimp_1</td>
<td></td>
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<tr>
<td>2. This child thinks that people would not want to touch him/her.</td>
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<tr>
<td>bodyimp_2</td>
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<tr>
<td>3. This child feels unsure of himself/herself among strangers.</td>
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<tr>
<td>bodyimp_3</td>
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<tr>
<td>4. Changes in this child’s appearance have interfered with his/her relations.</td>
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<tr>
<td>bodyimp_4</td>
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</tbody>
</table>

PEDIMobility

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.)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Unable =1</th>
<th>Hard= 2</th>
<th>A little hard=3</th>
<th>Easy=4</th>
<th>88 / 99</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. When lying on belly, turns head to both sides</td>
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<tr>
<td>pedi_2</td>
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<tr>
<td>3. Sits on floor without support of pillow or couch</td>
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<tr>
<td>pedi_3</td>
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<tr>
<td>4. Walks while holding onto furniture or walls</td>
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<tr>
<td>pedi_4</td>
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<tr>
<td>6. Walks outdoors on grass, mulch or gravel</td>
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</tbody>
</table>
7. When running, is able to go around people and objects pedi 7

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.

<table>
<thead>
<tr>
<th>Behavior</th>
<th>0=Never or not true</th>
<th>1=Sometimes or somewhat true</th>
<th>2=Often or very true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Has temper tantrums or hot temper.</td>
<td></td>
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<tr>
<td>pedproxang01</td>
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<tr>
<td>2. Argues a lot with adults.</td>
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<tr>
<td>pedproxang02</td>
<td></td>
<td></td>
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<tr>
<td>3. Is easily annoyed by others</td>
<td></td>
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<tr>
<td>pedproxang06</td>
<td></td>
<td></td>
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<tr>
<td>4. Gets back at people</td>
<td></td>
<td></td>
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<tr>
<td>pedproxang08</td>
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</tr>
</tbody>
</table>

NIH Toolbox Anger Proxy 3-7 T-Score: thangtscore_proxy

NIH Toolbox Sadness (for children ages 3-7)
Please indicate how often or true the behavior is of your child.

<table>
<thead>
<tr>
<th>Behavior</th>
<th>0=Never or not true</th>
<th>1=Sometimes or somewhat true</th>
<th>2=Often or very true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is unhappy, sad or depressed.</td>
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<tr>
<td>pedproxdep03</td>
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<tr>
<td>2. Cries a lot.</td>
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<tr>
<td>pedproxdep05</td>
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<td></td>
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<tr>
<td>3. Seem lonel.</td>
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<tr>
<td>pedproxdep06</td>
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<td></td>
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<tr>
<td>4. Withdraws from peer activities.</td>
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<tr>
<td>pedproxdep13</td>
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</tr>
</tbody>
</table>

NIH Toolbox Sadness Proxy 3-7 T-Score: tbsadtscore_proxy

NIH Toolbox General Life Satisfaction (for children ages 3-7)
Indicate how much you agree or disagree:

<table>
<thead>
<tr>
<th>Agree or disagree:</th>
<th>1=Strongly disagree</th>
<th>2=Disagree</th>
<th>3=Neither agree nor disagree</th>
<th>4=Agree</th>
<th>5=Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child’s life is going well.</td>
<td></td>
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</tbody>
</table>

88 / 99
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
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</tbody>
</table>

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:

- 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.

<table>
<thead>
<tr>
<th>Does your child have problems…</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing? chcprox1, chcprox1a</td>
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<td></td>
<td></td>
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<tr>
<td>Yes = 1</td>
<td>No = 0</td>
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<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
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<tr>
<td>Yes = 1</td>
<td>No = 0</td>
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<tr>
<td>3. Learning and understanding? chcprox3, chcprox3a</td>
<td>Yes = 1</td>
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<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a</td>
<td>Yes = 1</td>
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<td>No = 0</td>
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<td>5. Controlling emotions or behavior? chcprox5, chcprox5a</td>
<td>Yes = 1</td>
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<td>6. with Seizures or epilepsy? chcprox6, chcprox6a</td>
<td>Yes = 1</td>
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<tr>
<td>No = 0</td>
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<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>Yes = 1</td>
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<tr>
<td>No = 0</td>
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<td>8. with Teeth and gums? chcprox8, chcprox8a</td>
<td>Yes = 1</td>
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<tr>
<td>No = 0</td>
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<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a</td>
<td>Yes = 1</td>
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<td>No = 0</td>
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<td>10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a</td>
<td>Yes = 1</td>
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<td>No = 0</td>
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<td>11. with Growth? chcprox11, chcprox11a</td>
<td>Yes = 1</td>
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<td>No = 0</td>
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<td>12. Sleeping? chcprox12, chcprox12a</td>
<td>Yes = 1</td>
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<tr>
<td>No = 0</td>
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<tr>
<td>13. with Repeated infections? chcprox13, chcprox13a</td>
<td>Yes = 1</td>
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<tr>
<td>No = 0</td>
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<tr>
<td>14. with Breathing (eg asthma)? chcprox14, chcprox14a</td>
<td>Yes = 1</td>
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<tr>
<td>No = 0</td>
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<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a</td>
<td>Yes = 1</td>
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<td>No = 0</td>
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<tr>
<td>16. with other Skin problems (eg eczema)? chcprox16, chcprox16a</td>
<td>Yes = 1</td>
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<td>No = 0</td>
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<tr>
<td>17. with the Heart (such as a birth defect)?</td>
<td>Yes = 1</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Variable names appear in red.

BMS Pediatric Parent Proxy 8-17 Codebook Form I
NewMSID_________

<table>
<thead>
<tr>
<th>chcprox17, chcprox17a</th>
<th>No=0</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. with Pain? chcprox18, chcprox18a</td>
<td>Yes=1</td>
</tr>
<tr>
<td></td>
<td>No=0</td>
</tr>
</tbody>
</table>

19. Does your child have any other health problems? chcprox19|Yes |No
If yes, specify problem: __chcprox19ot (text field)_________________

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

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

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

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

NIH Toolbox General Life Satisfaction
Indicate how much you agree or disagree:
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

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

   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

   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 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 your child have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? physprobprepx
   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? psychtrpx
   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) ethnicity
   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

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

2. After your child’s hospital discharge, where will he/she be living? (Choose only one) dislivsitprx
   1. □ House
   2. □ Apartment
   3. □ Mobile home
   4. □ Institution
   5. □ Homeless
   6. □ Other

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 com99. □ Unknown livhisdisprx_99

Interviewer instructions: Ask the question as open-ended.
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 ____

(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.”

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)

How many people are in your household? ________

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

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

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 _______________________________

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) spons

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)

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
   2. □ Sometimes
   3. □ Never

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

Approximately how many times during the 4 weeks before the burn did your child participate in the following activities outside of your home?
2: Shopping  
   ci3prx_pre
   1. □ Never
   2. □ 1-4 times
   3. □ 5 or more times

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

3: Leisure activities such as movies, sports, and restaurants.  
   ci4prx_pre
   1. □ Never
   2. □ 1-4 times
   3. □ 5 or more times

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

4: Visiting friends or relatives  
   ci5prx_pre

   88. □ Declined to answer/Refused
   99. □ Unknown
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
   2. □ Mostly with family members
   3. □ Mostly with friends who do not have burn injuries
   4. □ Mostly with friends
   5. □ With a combination of family and friends

6: Did your child have a best friend with whom he/she confided? ci7prx_pre
   1. □ Yes
   2. □ No

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

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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 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

**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.*
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?  
   - [ ] Yes
   - [ ] No
   
2. Since your last interview, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? 
   - [ ] Yes
   - [ ] No
   - [ ] Not applicable
   - [ ] Don’t know

3. Since the last interview, has your child received any of the following services at home or outpatient? (Choose all that apply)
   - [ ] No services
   - [ ] Occupational therapy
   - [ ] Physical therapy
   - [ ] Speech language pathology
   - [ ] Social work
   - [ ] Psychological services
   - [ ] Vocational services

   0=not checked
   1=checked

   Added in 2015

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

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

Since your last interview, where did your child receive his/her outpatient occupational or physical burn therapy? ther_brn_ctrprx
5. This clinical burn center?
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable (no OT/PT received)

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

7. Since your last interview [provide date], has your child had any burn related surgeries? surgery_fuprx
   1. ☐ Yes
   2. ☐ No
   99. ☐ Don't know

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
   2. ☐ No
   99. ☐ Don't know

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____________

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

1. Surgery for open wounds surgtypeprx___1
2. Surgery for joint contractures surgtypeprx___2
3. Surgery for scar management surgtypeprx___3
4. Amputation surgtypeprx___4
5. Other surgtypeprx___5 (if so, what? otrsurgprx____________________)
77. Not applicable (no surgery) surgtypeprx___77

0=not checked
1=checked

Added in 2015

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

**Amputations**

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

1. No amputfu1prx__1; 0=not checked; 1=checked
2. Yes, above elbow right amputfu1prx__2; 0=not checked; 1=checked
3. Yes, above elbow left amputfu1prx__3; 0=not checked; 1=checked
4. Yes, above elbow bilateral amputfu1prx__4; 0=not checked; 1=checked
5. Yes, below elbow right amputfu1prx__5; 0=not checked; 1=checked
6. Yes, below elbow left amputfu1prx__6; 0=not checked; 1=checked
7. Yes, below elbow bilateral amputfu1prx__7; 0=not checked; 1=checked
8. Yes, digits only right numudgtrfuprx____(fill in # of digits) (Thumb amputated? thumbfu1prx □
1-Yes 2-No, 99-Unknown) amputfu1prx___8; 0=not checked; 1=checked
9. Yes, digits only left numudgtrfuprx____(fill in # of digits) (Thumb amputated? thumbfu1prx □
1-Yes 2-No, 99-Unknown) amputfu1prx___9; 0=not checked; 1=checked
10. Yes, digits only bilateral numudgtrfuprx____(fill in # of digits) (Thumbs amputated? thumbfu2prx □
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
### 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

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:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>To a very small extent</td>
<td>To a small extent</td>
<td>To a moderate extent</td>
<td>To a fairly great extent</td>
<td>To a great extent</td>
<td>To a very great extent</td>
</tr>
</tbody>
</table>

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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.

<table>
<thead>
<tr>
<th>Does your child have problems…</th>
<th>Problem?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing? chcprox1, chcprox1a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
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<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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<tr>
<td>3. Learning and understanding? chcprox3, chcprox3a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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<tr>
<td>4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)? chcprox4, chcprox4a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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<tr>
<td>5. Controlling emotions or behavior? chcprox5, chcprox5a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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<tr>
<td>6. with Seizures or epilepsy? chcprox6, chcprox6a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcprox7, chcprox7a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. with Teeth and gums? chcprox8, chcprox8a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a</td>
<td>□ Yes=1 □ No=0</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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

11. with Growth?  chcprox11, chcprox11a
Yes=1  No=0

12. Sleeping?  chcprox12, chcprox12a
Yes=1  No=0

13. with Repeated infections?  chcprox13, chcprox13a
Yes=1  No=0

14. with Breathing (eg asthma)?  chcprox14, chcprox14a
Yes=1  No=0

15. with Chronic open skin areas (eg chronic open wounds)?  chcprox15, chcprox15a
Yes=1  No=0

16. with other Skin problems (eg eczema)?  chcprox16, chcprox16a
Yes=1  No=0

17. with the Heart (such as a birth defect)?  chcprox17, chcprox17a
Yes=1  No=0

18. with Pain?  chcprox18, chcprox18a
Yes=1  No=0

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:

<table>
<thead>
<tr>
<th></th>
<th>Definitely true=1</th>
<th>Mostly true=2</th>
<th>Not sure=3</th>
<th>Mostly false=4</th>
<th>Definitely false=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. This child feels that the burn is unattractive to others. <strong>bodyimp_1</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. This child thinks that people would not want to touch him/her. <strong>bodyimp_2</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. This child feels unsure of himself/herself among strangers. <strong>bodyimp_3</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Changes in this child’s appearance have interfered with his/her relationships. <strong>bodyimp_4</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### PROMIS-Anger

In the past 7 days…

<table>
<thead>
<tr>
<th></th>
<th>0= Neve</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child felt mad <strong>pf1anger1</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. My child was so angry he/she felt like yelling at somebody <strong>pf1anger5</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. My child was so angry he/she felt like throwing something <strong>pf1anger3</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. My child felt upset <strong>pf1anger10</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. When my child got mad, he/she stayed mad <strong>pf1anger8</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### PROMIS Depressive Symptoms

In the past 7 days…

<table>
<thead>
<tr>
<th></th>
<th>0= Neve</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child could not stop feeling sad <strong>pf2depr7</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. My child felt everything in his/her life went wrong <strong>pf1depr7</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. My child felt like he/she couldn’t do anything right <strong>pf1depr5</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. My child felt lonely <strong>pf2depr10</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. My child felt sad <strong>pf2depr3</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. My child thought that his/her life was bad <strong>pf2depr5</strong></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### PROMIS-Pain Interference

**PROMIS Depressive Symptoms T-Score Variable: deptscore_proxy**
Table: BMS Pediatric Proxy 8-17 Codebook Form II

**In the past 7 days…**

<table>
<thead>
<tr>
<th>Question</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child had trouble sleeping when he/she had pain pf2pain5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My child felt angry when he/she had pain pf3pain7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My child had trouble doing schoolwork when he/she had pain pf2pain2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. It was hard for my child to pay attention when he/she had pain pf3pain2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. It was hard for my child to run when he/she had pain pf2pain4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. It was hard for my child to walk one block when he/she had pain pf1pain4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. It was hard for my child to have fun when he/she had pain pf3pain4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. It was hard for my child to stand when he/she had pain pf4pain6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4= Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child felt accepted by other kids his/her age pf3socabi9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My child was able to count on his/her friends pf4socabi12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My child was good at making friends pf3socabi4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. My child and his/her friends helped each other out pf2socrole4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Other kids wanted to be my child’s friend pf1socabi2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Other kids wanted to be with my child pf3socrole4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Other kids wanted to talk to my child pf2socabi9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PROMIS Peer Relationships T-Score: peertscore_proxy**

<table>
<thead>
<tr>
<th>Question</th>
<th>4=with no trouble</th>
<th>3=with a little trouble</th>
<th>2= With some trouble</th>
<th>1= With a lot of trouble</th>
<th>0=Not able to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child could do sports and exercise that other kids his/her age could do pf1mobil3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. My child could get up from the floor \( \text{pf3mobil9} \)  
3. My child could keep up when he/she played with other kids \( \text{pf4mobil4} \)  
4. My child could move his/her legs \( \text{pf3mobil8} \)  
5. My child could stand up without help \( \text{pf3mobil3} \)  
6. My child could stand up on his/her tiptoes \( \text{pf2mobil7} \)  
7. My child could walk up stairs without holding on to anything \( \text{pf2mobil4} \)  
8. My child has been physically able to do the activities he/she enjoys most \( \text{pf1mobil1} \)

**PROMIS Physical Function Mobility T-Score: pfmobtscore_proxy**

**PROMIS-Physical function Upper Extremity**

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>4=with no trouble</th>
<th>3=with a little trouble</th>
<th>2=With some trouble</th>
<th>1=With a lot of trouble</th>
<th>0=Not able to do</th>
</tr>
</thead>
</table>
| 1. My child could button his/her shirt or pants \( \text{pf2uprext3} \)  
2. My child could open a jar by himself/herself \( \text{pf4uprext1} \)  
3. My child could open the rings in school binders \( \text{pf3uprext11} \)  
4. My child could pour a drink from a full pitcher \( \text{pf4uprext10} \)  
5. My child could pull a shirt on over his/her head without help \( \text{pf3uprext4} \)  
6. My child could pull open heavy doors \( \text{pf3uprext9} \)  
7. My child could put on his/her shoes without help \( \text{pf2uprext2} \)  
8. My child could use a key to unlock a door \( \text{pf3uprext7} \)  | | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  

**PROMIS Upper Extremity T-Score: pfuptscore_proxy**

**NIH Toolbox General Life Satisfaction**

<table>
<thead>
<tr>
<th>Indicate how much you agree or disagree:</th>
<th>1= Strongly disagree</th>
<th>2= Disagree</th>
<th>3= Neither agree nor disagree</th>
<th>4= Agree</th>
<th>5= Strongly agree</th>
</tr>
</thead>
</table>
| 1. My child’s life is going well. \( \text{papxy066} \)  
2. My child's life is just right. \( \text{papxy067} \)  
3. My child has a good life. \( \text{papxy070} \)  
4. My child has what he/she wants in | | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  
| | | | | | 88 / 99  

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__________**

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

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0= Never</th>
<th>1= Almost Never</th>
<th>2= Sometimes</th>
<th>3= Often</th>
<th>4=Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child had trouble sleeping when he/she was itching</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. My child felt angry when he/she was itching</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. My child had trouble doing schoolwork when he/she was itching</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. It was hard for my child to pay attention when he/she was itching</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. It was hard for my child to have fun when he/she was itching</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

**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 livingafu___88
   5. □ Other relative (siblings, grandparents) livingafu___5 99. □ Unknown livingafu___99
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, or 24 month follow-up, ask…

7. …is it the same program or a new program as compared with your last interview? (Or, as compared with before his/her burn injury, if this is a 6 month follow-up). aprogfuprx  

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

   1. ☐ Same program full time  
   2. ☐ Same program part time  
   3. ☐ New program full time  
   4. ☐ New program part time  
   5. ☐ Did not resume school  
   6. ☐ Returned to individual program, home school  
   7. ☐ Not in school

_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)

_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.

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

   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? disincbrnpx
       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)? physprobfuppx
    1. ☐ Yes  2. ☐ No  88. ☐ Declined to answer/Refused
       99. ☐ Unknown

14. Does your currently have any psychological issues, such as depression or anxiety? psychisfuppx
    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)? ________________ hincnumfuppx
    (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.” hinccatfuppx
   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)
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

**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

3: Leisure activities such as movies, sports, and restaurants. **ci4prx**

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

4: Visiting friends or relatives **ci5prx**

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

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

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: ____________