Burn Model System Survey Codebooks

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

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

Numbers for response categories correspond to codes unless otherwise noted.

These Codebooks include:

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

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

NewMSID (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

PS2. Was patient alive at discharge? alive_dc
1. □ Yes
2. □ No

PS3. Consent at discharge for follow-up? consented
1. □ Yes, consented (continue to PS4)
2. □ No, did not consent/refused (do not collect DOB or Date of Burn, skip PS4 and PS6)
3. □ No, did not consent/missed (do not collect DOB or Date of Burn, skip PS4 and PS6)
4. □ Eligible but unable to consent (severe cognitive impairment due to dementia, TBI, etc) (do not collect DOB or Date of Burn, skip PS4 and PS6)
5. □ Eligible but unable to consent (language barriers) (do not collect DOB or Date of Burn, skip PS4 and PS6)

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

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

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

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

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

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

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

PS12. Date of discharge from acute burn care (does not include inpatient rehab)
   __disch_date_________________ (yyyy/mm/dd)
   **Coding:**
   1900/07/07 = not yet determined
   1900/09/09 = unknown
PS13. Date of 2\textsuperscript{nd} discharge from acute burn care \textit{(if applicable, does not include inpatient rehab)}

\begin{verbatim}
__
disch_date_2nd____________ (yyyy/mm/dd)
\end{verbatim}

\textit{Coding:}
\begin{itemize}
  \item 1900/07/07 = not yet determined
  \item 1900/08/08 = not applicable (no 2\textsuperscript{nd} discharge)
  \item 1900/09/09 = unknown
\end{itemize}

PS14. Date consent form signed by participant __
cnsnt_date__________ (yyyy/mm/dd)

\textit{Coding:}
\begin{itemize}
  \item 1900/07/07 = not yet determined
  \item 1900/08/08 = not applicable
  \item 1900/09/09 = unknown
\end{itemize}

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

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

\textit{Coding:}
\begin{itemize}
  \item 1900/07/07 = not yet determined
  \item 1900/08/08 = not applicable (no return to work or school)
  \item 1900/09/09 = unknown
\end{itemize}

PS16. Date of death: ___
dth_date___________ (yyyy/mm/dd)

\textit{Coding:}
\begin{itemize}
  \item 1900/07/07 = not yet determined
  \item 1900/08/08 = not applicable (Person Alive)
  \item 1900/09/09 = unknown
\end{itemize}

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

\textit{Coding:}
\begin{itemize}
  \item 77777 - Expired: Cause Unknown;
  \item 88888 - Not Applicable (Person Alive);
  \item 99999 - Unknown
\end{itemize}


\textit{Coding:}
\begin{itemize}
  \item 77777 - Expired: Cause Unknown;
  \item 88888 - Not Applicable (Person Alive);
  \item 99999 - Unknown
\end{itemize}


\textit{Coding:}
\begin{itemize}
  \item 77777 - Expired: Cause Unknown;
  \item 88888 - Not Applicable (Person Alive);
  \item 99999 - Unknown
\end{itemize}
NewMSID__________

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

NewMSID ________________________________

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

MR1. Main cause of burn injury (primary etiology) Pretiol
  1. Fire/flame
  2. Scald
  3. Contact with hot object
  4. Grease
  5. Tar
  6. Chemical
  7. Hydrofluoric acid
  8. Electricity
  9. Radiation
 10. UV light
 11. Other burn
 15. Flash burn
 99. Unknown

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

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

Source of MR2: src_placeinj
  1. Medical record
  2. Self report
Variable names and information are indicated in red

BMS Form I Medical Record Abstraction

NewMSID__________

MR3. Location of burn injury: locinj
1. □ Patient’s home
2. □ Other private dwelling
3. □ Patient’s place of work
4. □ Other building or structure
5. □ Conveyance (auto, plane, etc)
6. □ Other
99. □ Unknown
Source of MR3: src_locinj
1. □ Medical record
2. □ Self report

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

MR5. Disposition: disposn
1. □ Died, burn related
2. □ AMA/Unable to complete treatment
3. □ Discharged, patient home
4. □ Discharged, other home *(includes hospital owned apartments)*
6. □ Discharged, extended care facility
8. □ Discharged, other rehab facility *(not model system)*
9. □ Discharged, institution
10. □ Discharged, drug/alcohol treatment center
11. □ Discharged, shelter
12. □ Discharged, street
13. □ Died, non-burn related
14. □ Other
99. □ Unknown
Source of disposition: src_disposn
1. □ Medical record
2. □ Self report

Note:
Text field, othrehabnote, added to REDCap in March 2018, including information from Boston IRF project. This text field captures more information about category 8, other rehab facility.
BMS Form I Medical Record Abstraction

NewMSID__________

MR6. Primary sponsor of care at hospital discharge, or who is paying for the majority of burn care costs (choose only one)? pay_dc
1. [ ] Medicare
2. [ ] Medicaid (DSHS)
3. [ ] Private insurance/HMO/PPO/Pre-paid/Managed Care
4. [ ] Worker’s compensation (L&I)
5. [ ] Champus/Tri-Care
6. [ ] Self-pay or indigent (public support)
7. [ ] VA
8. [ ] Other
9. [ ] Philanthropy (private support or private foundation or Shriners hospital)
99. [ ] Unknown

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

MR7. Total number of days on inpatient rehab unit: __rhh_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) trmkbrn
1. [ ] Yes
2. [ ] No
99. [ ] Unknown

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

MR12. Perineum (buttock, genitals) peribrn
1. [ ] Yes
2. [ ] No
99. [ ] Unknown

Notes:
Parenthetical statement (buttock, genitals) added to variable with new Forms in 2015
Variable names and information are indicated in red

BMS Form I Medical Record Abstraction

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) farmbnrn (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

Parts of body grafted:

MR18. Head/Face/Neck hngrft
   1. □ Yes  2. □ No  99. □ Unknown
Notes: “Face” added to variable with new Forms in 2015

MR19. Trunk (back, chest, abdomen) trnkgrft
   1 □ Yes  2. □ No  99. □ Unknown
Notes: Parenthetical statement (back, chest, abdomen) added to variable with new Forms in 2015

MR20. Perineum (buttock, genitals) perigrft
   1 □ Yes  2. □ No  99. □ Unknown
Notes: Parenthetical statement (buttock, genitals) added to variable with new Forms in 2015

MR21. Shoulder/Upper Arm/Elbow suegrft (variable name prior to 1/15, with arm data, was armgrft)
   2. □ Left  4. □ None

MR22. Forearm (includes wrist) farmgrft (variable name prior to 1/15, with arm data, was armgrft)
   2. □ Left  4. □ None
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): tbsagrt (XX.X) (code 999 for unknown)

MR28. Days on ventilator: __daysgrft__________________ (code 999 for unknown)

MR29. Number of trips to the operating room since injury (other than dressing changes), burn or non-burn related: __numtrpor________________________ (code 999 for unknown)

MR30. Tracheostomy? trach
   1 □ Yes     2. □ No     99. □ Unknown
   Notes: New variable added with new Forms in 2015

MR31. Documented range of motion deficits romdef (previously collected variable was contrctr)
   1. □ Yes
   2. □ No
   3. □ Not evaluated
   99. □ Unknown

MR32. Amputation(s) due to burn at discharge? amputbrn
   1 □ Yes     2. □ No     99. □ Unknown

MR33. Upper extremity amputation (choose all that apply) amput1
   1. □ Yes, above elbow right amput1__1
   2. □ Yes, above elbow left amput1__2     0 = checked
   3. □ Yes, above elbow bilateral amput1__3   1 = not checked
   4. □ Yes, below elbow right amput1__4
   5. □ Yes, below elbow left amput1__5
   6. □ Yes, below elbow bilateral amput1__6
   7. □ Yes, digits only right numudgtr (fill in # of digits) amput1__7
       (Thumb amputated? thumbr □1 Yes □2 No)
   8. □ Yes, digits only left numudgtl (fill in # of digits) amput1__8
       (Thumb amputated? thumbl □1 Yes □2 No)
BMS Form I Medical Record Abstraction

NewMSID_________

9. □ Yes, digits only bilateral numudgtr (fill in # of digits) amput1__9
   (Thumbs amputated? thumbb □ 1 Yes □ 2 No)
   6 = checked

10. □ No amput1__10
    0 = not checked

99. □ Unknown amput1__99
    1 = not checked

Notes:
New variable added with new Forms in 2015

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

1. □ Yes, above knee right amput2__1
2. □ Yes, above knee left amput2__2
   0 = not checked
3. □ Yes, above knee bilateral amput2__3
   1 = checked
4. □ Yes, below knee right amput2__4
5. □ Yes, below knee left amput2__5
6. □ Yes, below knee bilateral amput2__6
7. □ Yes, digits only right numudgtr (fill in # of digits) amput2__7
8. □ Yes, digits only left numudfl (fill in # of digits) amput2__8
9. □ Yes, digits only bilateral numudgtr (fill in # of digits) amput2__9
10. □ Transmetatarsal right (partial foot amputation right) amput2__10
11. □ Transmetatarsal left (partial foot amputation left) amput2__11
12. □ Transmetatarsal bilateral (partial foot amputation bilateral) amput2__12
13. □ No amput2__13
99. □ Unknown amput2__99

Notes:
New variable added with new Forms in 2015

MR35. Hand dominance handdom

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

Notes:
New variable added with new Forms in 2015

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

1 □ Yes
2. □ No
99. □ Unknown

Notes:
New variable added with new Forms in 2015

MR37. Heterotopic ossification at discharge? hodc

1 □ Yes
2. □ No
99. □ Unknown

MR38. Height at admission (centimeters) ______heightad______(code 999 for unknown)

MR39. Weight at admission (kilograms) ______weightad______(code 999 for unknown)

MR40. Height at discharge (centimeters) ______htdc______(code 999 for unknown)
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
### Co-Morbidities List

<table>
<thead>
<tr>
<th>Condition</th>
<th>Code</th>
<th>Yes</th>
<th>No</th>
<th>Missing/Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension or high blood pressure?</td>
<td>highbp</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Congestive heart failure?</td>
<td>conghf</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Myocardial infarction or heart attack?</td>
<td>heartatk</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Heart arrhythmias?</td>
<td>heartar</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Stroke?</td>
<td>stroke</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Emphysema or asthma or COPD?</td>
<td>copd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>High blood cholesterol?</td>
<td>highchol</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Diabetes, high blood sugar, or sugar in the urine?</td>
<td>diabetes</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Pneumonia?</td>
<td>pneum</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Liver disease (such as hepatitis)?</td>
<td>hepat</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Rheumatoid arthritis?</td>
<td>rheum</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Osteoarthritis?</td>
<td>osteo</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Sleep disorder like sleep apnea?</td>
<td>sleepdis</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Cataracts?</td>
<td>catar</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Chronic pain?</td>
<td>chronpa</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Dementia of some kind, like Alzheimer's?</td>
<td>alzh</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Parkinson's disease?</td>
<td>parkd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Alcoholism?</td>
<td>etohadd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Drug addiction?</td>
<td>drugadd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Depression?</td>
<td>depress</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Anxiety?</td>
<td>anx</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Panic attacks?</td>
<td>panic</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Bipolar disorder or manic-depression?</td>
<td>bipol</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD)?</td>
<td>adhd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Obsessive-compulsive disorder?</td>
<td>ocd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>PTSD (post-traumatic stress disorder)?</td>
<td>ptsd</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Spinal cord injury?</td>
<td>sci</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
<tr>
<td>Traumatic brain injury?</td>
<td>tbi</td>
<td>1</td>
<td>2</td>
<td>99</td>
</tr>
</tbody>
</table>
**Pain Medication Data Collection Table**

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

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No pain medication</td>
<td>pmed_dis___0</td>
</tr>
<tr>
<td>1</td>
<td>Methadone</td>
<td>pmed_dis___1</td>
</tr>
<tr>
<td>2</td>
<td>Codeine</td>
<td>pmed_dis___2</td>
</tr>
<tr>
<td>3</td>
<td>Hydrocodon (Norco, Vicoden)</td>
<td>pmed_dis___3</td>
</tr>
<tr>
<td>4</td>
<td>Oxycodone (Percodet, OxyContin)</td>
<td>pmed_dis___4</td>
</tr>
<tr>
<td>5</td>
<td>Hydromorphone (Dilaudid)</td>
<td>pmed_dis___5</td>
</tr>
<tr>
<td>6</td>
<td>Fentanyl (Duragesic)</td>
<td>pmed_dis___6</td>
</tr>
<tr>
<td>7</td>
<td>Morphine</td>
<td>pmed_dis___7</td>
</tr>
<tr>
<td>8</td>
<td>Acetaminophen with codeine (Tylenol #3)</td>
<td>pmed_dis___8</td>
</tr>
<tr>
<td>9</td>
<td>Gabapentin (Neurontin)</td>
<td>pmed_dis___9</td>
</tr>
<tr>
<td>10</td>
<td>Amitriptyline</td>
<td>pmed_dis___10</td>
</tr>
<tr>
<td>99</td>
<td>Unknown</td>
<td>pmed_dis___99</td>
</tr>
</tbody>
</table>

Name of Pain Medication (prescribed at discharge), if other than above (text field for name of medication)

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>meddis1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>meddis2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>meddis3</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>meddis4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>meddis5</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>meddis6</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>meddis7</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>meddis8</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>meddis9</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>meddis10</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>meddis11</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>meddis12</td>
<td></td>
</tr>
</tbody>
</table>
Today's Date: ___ ___ / ___ ___ / ________

(Note: First page is for research staff use only)

Indicate time survey started: ____________

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

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

3. Checklist of forms: mark when each is complete status
   1. ☐ Patient Status Form status___1
   2. ☐ Medical Record Abstraction Form status___2 0 = not checked
   3. ☐ Review of Systems Checklist Form status___3 1 = checked
   4. ☐ Form I status___4

Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

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

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

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

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

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

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

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

Satisfaction with Life: PRE-BURN

Here are 5 statements with which you may agree or disagree. Using a scale where 1 represents you strongly disagree and 7 represents that you strongly agree, indicate your agreement with each item by the appropriate choice as it was 4 weeks prior to your burn. Please be open and honest in your response.

<table>
<thead>
<tr>
<th>1. In the 4 weeks before my burn, in most ways my life was close to ideal: sl1_pre</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>2. In the 4 weeks before my burn, the conditions of my life were excellent: 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>
<td></td>
<td></td>
</tr>
<tr>
<td>5. In the 4 weeks before my burn, if I could have lived my life over, I would have changed almost nothing: sl5_pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Satisfaction with Life Total Score: swlscore_pre
The next questions I have are about activities you might have participated in before your burn injury.

During the 4 weeks before your burn:
1: Who usually looked after your personal finances, such as banking and paying bills? cia2_pre
   1. Yourself alone  88. Declined to answer/Refused
   2. Yourself and someone else  99. Unknown
   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 cia3_pre
   1. Never  88. Declined to answer/Refused
   2. 1-4 times
   3. 5 or more times

3: Leisure activities such as movies, sports, and restaurants. cia4_pre
   1. Never  88. Declined to answer/Refused
   2. 1-4 times
   3. 5 or more times

4: Visiting friends or relatives cia5_pre
   1. Never  88. Declined to answer/Refused
   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? cia6_pre
   1. Mostly alone  88. Declined to answer/Refused
   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
   77. Not applicable (no leisure activities)

6: Did you have a best friend with whom you confided? cia7_pre
   1. Yes  88. Declined to answer/Refused
   2. No

Community Integration Questionnaire Social Integration Score: ciqsic_pre
**VR-12: PRE-BURN**

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

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

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

<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. 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  

   b. Climbing several flights of stairs? vr12pre2b  

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?  

   a. Accomplished less than you would like. vr12pre3a  

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

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

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:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did you feel calm and peaceful? vr12pre6a</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b. Did you have a lot of energy? vr12pre6b</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c. Did you feel downhearted and blue? vr12pre6c</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>
<thead>
<tr>
<th>TIME</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>VR-12 Mental Health Component Score: Pre Total Score Variable: mcs_vr12_pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VR-12 Physical Health Component Score: Pre Total Score Variable: pcs_vr12_pre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**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

4. Did you receive psychological therapy or counseling in the last 12 months? psychtr
   - 1. Yes
   - 2. No

**Pre-Injury Demographics**

1. Before your burn injury, where were you living? (Choose only one) resdenc
   - 1. Private residence
   - 2. Nursing home
   - 3. Adult home
   - 4. Correctional institution
   - 5. Hotel/motel
   - 6. Homeless
   - 7. Hospital

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

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

2. What was your zip code at the time of your burn injury? ____ ____ ____ ____ zip_pre
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for not applicable/homeless)

Added to data collection forms in 2015.
3. Who were you living with before your burn injury? (Choose all that apply)
   1. ☐ 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

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

4. What was your marital status at the time of your burn injury? (Choose only one) marstatpre
   1. ☐ Married; living common-law or with a partner
   2. ☐ Separated
   3. ☐ Divorced
   4. ☐ Widowed
   5. ☐ Single (not married)

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

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

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

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

   1. ☐ 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)

6. How many people are in your household? numhspre
   (Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)
7. In the year prior to your burn injury, how many months did you work at a regular job?  

(fill in # of months)  

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

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

Added to data collection forms in 2015.

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

Occupation: ________________

Code: ________________

*Added to data collection forms in 2015.*

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

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

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

1. □ Working  
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".
10. Before your burn, about how many **hours a week** did you work for pay? ________________ **hpaypre**

   (Interviewer Instructions: fill in hours)
   777. ☐ Not applicable (not employed)
   888. ☐ Declined to answer/Refused
   999. ☐ Unknown

**Interviewer Instructions:** Skip #11 and move on to #12 on the next page if the participant declined to answer the household income question or if the participant is a one-person household (fill in income from household question if the participant is a one-person household).

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

   If clarification about currency is needed, say, **“these categories are in U.S. dollar amounts.”**
   1. ☐ Less than $25,000
   2. ☐ $25,000-$40,999
   3. ☐ $41,000-$55,999
   4. ☐ $56,000-$70,999
   5. ☐ $71,000-$85,999
   6. ☐ $86,000-$100,000
   7. ☐ Greater than $100,000
   8. ☐ Living outside the United States
   77. ☐ Not applicable (no individual income)

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

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

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

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

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

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

   1. ☐ Burn related **(This response is N/A for discharge)**
   2. ☐ Medical problems other than your burn injury.
   3. ☐ Problems with employer
   4. ☐ Emotional/social
   5. ☐ Legal/jail
   6. ☐ Substance abuse
   7. ☐ Personal choice
   8. ☐ Other
   9. ☐ Retired **Response option added with 2015 forms**
   11. ☐ Unemployed but actively seeking employment **Response option added with 2015 forms**
   77. ☐ Not applicable (working or going to school) **Response option added with 2015 forms**
14. Before the burn, did you have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)? \textit{physprobpre} (this variable replaced “physdis” in 2015)
   \begin{itemize}
   \item 1. Yes
   \item 2. No
   \end{itemize}

15. Before the burn, did you have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? \textit{cogimppre}
   \begin{itemize}
   \item 1. Yes
   \item 2. No
   \end{itemize}

16. Before your burn injury, were you ever told by a doctor that you had any of the following psychological issues (choose all that apply)? \textit{psych}
   \begin{itemize}
   \item 1. Depression
   \item 2. Bipolar disorder
   \item 3. Anxiety
   \item 4. Post-Traumatic Stress Disorder (PTSD)
   \item 5. Schizophrenia/psychotic disorder
   \item 6. Other, please explain: \underline{psychlistot}
   \end{itemize}

\textbf{CAGE Alcohol use}: 
\textit{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.

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.

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

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

In the past year…
   \begin{itemize}
   \item 1. Have you felt you needed to \textbf{Cut down on your drinking}? \hspace{1cm} \underline{Yes} (1) \hspace{1cm} \underline{No} (0)
   \item 2. Have people \textbf{Annoyed} you by criticizing your drinking? \underline{Yes} (1) \hspace{1cm} \underline{No} (0)
   \item 3. Have you ever felt \textbf{Guilty} about drinking? \underline{Yes} (1) \hspace{1cm} \underline{No} (0)
   \item 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? \underline{Yes} (1) \hspace{1cm} \underline{No} (0)
   \end{itemize}

\textbf{CAGE Drug use}:
\textit{Interviewer Instructions:} If clarification is needed, say, “We are interested in learning more about use of drugs like crack or heroin; or about prescription drugs like pain killers or stimulants that were not prescribed to you; or chemicals you might have inhaled or ‘huffed’. We also want to know if sometimes you took more than you should have of any drugs that have been prescribed to you.”

\textit{Interviewer Instructions:} If the participant states they do not use drugs after the first question, you can fill in “No” for all four questions and skip to the next section.
In the past year...
1. Have you ever felt you needed to Cut down on your drug use? □ Yes (1) □ No (0)

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

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

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

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

Patient’s history of alcohol abuse in the last 12 months: etohabu
1. □ Yes (C-A-G-E=2,3,4)
2. □ No (C-A-G-E=0,1)
88. □ Declined to answer/Refused
99. □ Unknown

Patient’s history of drug abuse in the last 12 months: drugabu
1. □ Yes (C-A-G-E=2,3,4)
2. □ No (C-A-G-E=0,1)
88. □ Declined to answer/Refused
99. □ Unknown

---

**Post-Injury Section**

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

**Pain**

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

<table>
<thead>
<tr>
<th>How would you rate your pain on average? global07_dis</th>
<th>0</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>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Worst imaginable pain</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Itch scale:
The next questions are about itching since your burn injury.

Currently, do you have any itching in the area of your burn, skin grafts, or donor sites? itchscr_dis
1. □ Yes
2. □ No (Interviewer Instructions: skip to Demographics on page 14)

1. Currently, how many hours a day are you itching? itch1_dis
   1. □ Less than 6 hours a day
   2. □ 6-12 hours a day
   3. □ 12-18 hours a day
   4. □ 18-23 hours a day
   5. □ All day
   77. □ Not applicable (no itching)

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

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

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

2. What is your ethnicity? ethnicity
   1. □ Hispanic or Latino
   2. □ Not Hispanic or Latino

3. What is your dominant hand? handdom
   1. □ Left
   2. □ Right
   3. □ Ambidextrous
   99. □ Don’t know

1. After your discharge, where will you be living? (Choose only one) dislivsit
   1. □ Private residence
   2. □ Nursing home
   3. □ Adult home
   4. □ Correctional institution
   5. □ Hotel/motel
   6. □ Homeless
   7. □ Hospital

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

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

2. Who will you be living with after hospital discharge? (Choose all that apply)
   1. □ Alone livhisdisprx__1
   2. □ Spouse/partner/significant other livhisdisprx__2
   3. □ Friend livhisdisprx__3
   4. □ Parent or step-parent livhisdisprx__4
   5. □ Other relative (siblings, grandparents) livhisdisprx__5
   6. □ Others, not part of family livhisdisprx__6
   7. □ Guardian livhisdisprx__7
   8. □ Young children livhisdisprx__8
   9. □ Adult children livhisdisprx__9

   0=Not checked
   1=Checked
   88. □ Declined to answer/Refused livhisdisprx__88
   99. □ Unknown livhisdisprx__99
3. How many years of education have you completed? *(Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, “If you have not graduated from high school, please indicate the number of years spent in school. If you have at least a high school diploma, please indicate the highest degree earned or worked toward post-high school.” If participant ties to count years rather than degree attained, use the prompt, “In other words, what is the highest level of education you have completed?”)*

**edudis**

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

1. □ 1 year or less
2. □ 2 years
3. □ 3 years
4. □ 4 years
5. □ 5 years
6. □ 6 years
7. □ 7 years
8. □ 8 years
9. □ 9 years
10. □ 10 years
11. □ 11 or 12 years; no diploma
12. □ High school diploma
13. □ Work towards Associate’s degree, vocational degree, or trade school diploma/certificate
14. □ Associate’s degree, vocational degree, or trade school diploma/certificate
15. □ Work towards Bachelor’s degree
16. □ Bachelor’s degree
17. □ Work towards Master’s degree
18. □ Master’s degree
19. □ Work towards doctorate level degree
20. □ Doctoral level degree
66. □ Other

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

1. □ No
2. □ Yes
77. □ Not applicable  

**Variable added in 2015**

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

1. □ 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*
6. Were you ever incarcerated for conviction of a felony? *felsdis*
   1. ☐ No
   2. ☐ Yes  Variable added in 2015

7. While in school, were you ever classified as a special education student? *speducdis*
   1. ☐ No
   2. ☐ Yes  Variable added in 2015

8. Have you ever served in the military? *mildis*
   1. ☐ No
   2. ☐ Yes  Variable added in 2015

Is there anything else you would like to tell us? __________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________

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

*Indicate time survey ended:* ____________
Burn Model System Adult Form II Cover Sheet

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

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

These include:

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

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

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

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

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

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

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

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

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

1. Since the last follow-up, has the participant had any burn related surgeries (such as surgeries for open wounds or scar management)? surgery_fu_mra
   1. [ ] Yes
   2. [ ] No
   99. [ ] Don’t know

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

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

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

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

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

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

Amputations

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

1. Upper extremity amputation due to burn injury since last follow-up? (Choose all that apply)
   1. [ ] No amputfu1
   2. [ ] Yes, above elbow right amputfu1__2
   3. [ ] Yes, above elbow left amputfu1__3
   4. [ ] Yes, above elbow bilateral amputfu1__4
   5. [ ] Yes, below elbow right amputfu1__5
   6. [ ] Yes, below elbow left amputfu1__6
   7. [ ] Yes, below elbow bilateral amputfu1__7
   8. [ ] Yes, digits only right numudgtrfu (fill in # of digits) amputfu1__8
      (Thumb amputated? thumbfu 1 Yes 2 No)
   9. [ ] Yes, digits only left numudgltfu (fill in # of digits) amputfu1__9
      (Thumb amputated? thumbltfu 1 Yes 2 No)
   10. [ ] Yes, digits only bilateral (fill in # of digits) amputfu1__10
      (Thumbs amputated? thumbbfu 1 Yes 2 No)
   77. [ ] Not applicable (no amputations) amputfu1__77

Notes: New variable added with new Forms in 2015
2. Lower extremity amputation due to burn injury since last follow-up? (Choose all that apply)
   1. ☐ No amputfu2__1
   2. ☐ Yes, above knee right amputfu2__2
   3. ☐ Yes, above knee left amputfu2__3
   4. ☐ Yes, above knee bilateral amputfu2__4
   5. ☐ Yes, below knee right amputfu2__5
   6. ☐ Yes, below knee left amputfu2__6
   7. ☐ Yes, below knee bilateral amputfu2__7
   8. ☐ Yes, digits only right numldgtrfu__ (fill in # of digits) amputfu2__8
   9. ☐ Yes, digits only left numldgtlfu__ (fill in # of digits) amputfu2__9
   10. ☐ Yes, digits only bilateral numldgtbfu__ (fill in # of digits) amputfu2__10
   11. ☐ Transmetatarsal right (partial foot amputation right) amputfu2__11
   12. ☐ Transmetatarsal left (partial foot amputation left) amputfu2__12
   13. ☐ Transmetatarsal bilateral (partial foot amputation bilateral) amputfu2__13
   77. ☐ Not applicable (no amputations) amputfu2__77

Notes:
New variable added with new Forms in 2015

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

0. ☐ No pain medication pmed_fup___0 0 = not checked
1. ☐ Methadone pmed_fup___1 1 = checked
2. ☐ Codeine pmed_fup___2
3. ☐ Hydrocodon (Norco, Vicoden) pmed_fup___3
4. ☐ Oxycodone (Percocet, OxyContin) pmed_fup___4
5. ☐ Hydromorphone (Dilaudid) pmed_fup___5
6. ☐ Fentanyl (Duragesic) pmed_fup___6
7. ☐ Morphine pmed_fup___7
8. ☐ Acetaminophen with codeine (Tylenol #3) pmed_fup___8
9. ☐ Gabapentin (Neurontin) pmed_fup___9
10. ☐ Amitriptyline pmed_fup___10
99. ☐ Unknown pmed_fup___11
## Pain Medication Table

<table>
<thead>
<tr>
<th>Name of Pain Medication (prescribed in data collection window), if other than above</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. med1</td>
<td></td>
</tr>
<tr>
<td>2. med2</td>
<td></td>
</tr>
<tr>
<td>3. med3</td>
<td></td>
</tr>
<tr>
<td>4. med4</td>
<td></td>
</tr>
<tr>
<td>5. med5</td>
<td></td>
</tr>
<tr>
<td>6. med6</td>
<td></td>
</tr>
<tr>
<td>7. med7</td>
<td></td>
</tr>
<tr>
<td>8. med8</td>
<td></td>
</tr>
<tr>
<td>9. med9</td>
<td></td>
</tr>
<tr>
<td>10. med10</td>
<td></td>
</tr>
<tr>
<td>11. med11</td>
<td></td>
</tr>
<tr>
<td>12. med12</td>
<td></td>
</tr>
</tbody>
</table>
BMS Adult Interview Form II
NewMSID__________

Today's Date: ___ ___ / ___ ___ / ___ ___ fup_date
(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: __fup_start_time_

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

1. Follow-up period follow_up
   1. [ ] 6-month follow-up
   2. [ ] 12 month follow-up
   3. [ ] 24 month follow-up
   4. [ ] 5 year follow-up
   5. [ ] 10 year follow-up
   6. [ ] 15 year follow-up
   7. [ ] 20 year follow-up
   8. [ ] Other: ________

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

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

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

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

   Previous variable was called “admin_2”.

4. What is the status of this follow-up assessment? (Choose only one) lostfolo
   1. [ ] Some or all assessment done
   2. [ ] Death due to burn related complications
   3. [ ] Death due to non-burn related complications
   4. [ ] Unable to locate
   5. [ ] Refused this assessment
   6. [ ] Unable to test/med comp/incapable of responding
   7. [ ] Failed to respond
   8. [ ] Did not consent to future assessment/withdrew
   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
15. □ Death (unknown causes) (Interviewer Instructions: Update date and cause of death on Patient Status Form) Option 15 added with new forms in 2018

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

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

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

**Introduction script:**

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

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

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

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

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

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

1. What is your primary mode of transportation? transport
   1. □ Driving my own vehicle
   2. □ Riding with someone else
   3. □ Public transit
   77. □ Not applicable (I don’t use motorized transport)

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

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

Added in 2015

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

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

   1. □ No services services___1 (Interviewer Instructions: skip to #7, surgery item, on page 4)
   2. □ Occupational therapy services___2 88. □ Declined to answer/Refused services___88
   3. □ Physical therapy services___3 99. □ Unknown services___99
   4. □ Speech language pathology services___4
   5. □ Social work services___5 0 = not checked
   6. □ Psychological services services___6 1 = checked
   7. □ Vocational services services___7

Added in 2015

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

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

4. How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? numther
   1. □ One
   2. □ 2-4
   3. □ 5-10
   4. □ More than 10
   77. □ No PT/OT (skip to #7, surgery item, on page 4)

Previous variable “numserv” was changed to be multiple choice rather than fill in the blank. Data from “numserv” was categorized and then moved into “numther.” “Numserv” was archived.
Since your last interview, where did you receive your outpatient occupational or physical burn therapy?

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

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 (such as surgeries for open wounds or scar management)? surgery_fu
   1. ☐ Yes
   2. ☐ No
   99. ☐ Don’t know (Interviewer Instructions: skip to Review of Systems, below)

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

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

8. Have you had any burn-related surgeries outside of [name the BMS center]? surgout
   1. ☐ Yes
   2. ☐ No
   99. ☐ Don’t know (Interviewer Instructions: skip to Review of Systems, below)

Added in 2015

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

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

<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>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Change in voice?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Vision problems not corrected by glasses or contact lenses?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Eyelid problems?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Excessive tearing of the eyes?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Difficulty with memory?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Difficulty with thought processing?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. Numbness, pins and needles or burning sensations in your burn scar?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. Numbness, pins and needles or burning sensations in your hands?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. Numbness, pins and needles or burning sensations in your feet?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. Trouble with your balance?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
### Pain Medication

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

5. Since your last research study questionnaire, have you received psychological therapy or counseling due to your burn injury? *psychther*
   - 1. Yes
   - 2. 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
- 2. No (*Interviewer instructions: skip to the VR12 section on page 7*)
1. During the last two weeks, how many hours a day have you been itching? itch1
   1. □ Less than 6 hours a day 88. □ Declined to answer/Refused
   2. □ 6-12 hours a day 99. □ Unknown
   3. □ 12-18 hours a day
   4. □ 18-23 hours a day
   5. □ All day
   77. □ Not applicable (no itching)

2. Please rate the intensity of your itching over the past two weeks: itch2
   1. □ Not present 88. □ Declined to answer/Refused
   2. □ Mild 99. □ Unknown
   3. □ Moderate
   4. □ Severe
   5. □ Unbearable
   77. □ Not applicable (no itching)

3. Over the past two weeks, has your itching gotten better or worse compared to the previous month? itch3
   1. □ Completely resolved 88. □ Declined to answer/Refused
   2. □ Much better, but still present 99. □ Unknown
   3. □ Little bit better, but still present
   4. □ Unchanged
   5. □ Getting worse
   77. □ Not applicable (no itching)

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

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not applicable</th>
<th>Never affects sleep</th>
<th>Occasionally delays falling asleep</th>
<th>Frequently delays falling asleep</th>
<th>Delays falling asleep and occasionally wakes me up at night</th>
<th>Delays falling asleep and frequently wakes me up at night</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep itch4</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
</tbody>
</table>

4-D Itch Total Scores:
itch_dur: Itch Duration Score
itch_deg: Itch Degree Score
itch_dir: Itch Direction Score
itch_dis: Itch Disability Score
itch_tot: Itch Total Score
**Interviewer Instructions: Reminder:** participants can skip any questions they do not want to answer. If they indicate that they don’t want to answer any VR12 question, let them skip it and move on to the next item. If they do not want to answer an item, circle “88/Refused” next that item on the Form and move on. If a response is missing, circle “99/Unknown” next to that question.

**VR-12:**

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

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

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

<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>

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

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? vr12_2a
   
<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>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

   b. Climbing **several** flights of stairs? vr12_2b
   
<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>1</td>
<td>2</td>
<td>3</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>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</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>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</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>
<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>
</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)?

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

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

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

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

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

a. Have you felt **calm and peaceful**? vr12_6a

<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>6</td>
</tr>
</tbody>
</table>

b. Did you have a **lot of energy**? vr12_6b

<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>6</td>
</tr>
</tbody>
</table>

8. **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

<table>
<thead>
<tr>
<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>
</tr>
</tbody>
</table>
Modified PROMIS Profile 29:

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

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

### PHYSICAL FUNCTION

<table>
<thead>
<tr>
<th>1. Are you able to do chores such as vacuuming or yard work? pfa11</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</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐ 5</td>
<td>☐ 4</td>
<td>☐ 3</td>
<td>☐ 2</td>
<td>☐ 1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Are you able to go up and down stairs at a normal pace? pfa11</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Are you able to go for a walk of at least 15 minutes? pfa11</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Are you able to run errands and shop? pfa11</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PROMIS Physical Function T-Score: pftscore

### ANXIETY

<table>
<thead>
<tr>
<th>In the past 7 days...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. I felt fearful edanx01</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</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></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>
<tr>
<td>9. I felt nervous edanx465</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I felt like I needed help for my anxiety edanx076</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Variables edanx465 and edanx076 added in 2018

PROMIS Anxiety T-Score: anxtscore
### In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.</td>
<td>I felt worthless</td>
<td>eddep04</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
</tr>
<tr>
<td>12.</td>
<td>I felt helpless</td>
<td>eddep06</td>
<td>□</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I felt depressed</td>
<td>eddep29</td>
<td>□</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I felt hopeless</td>
<td>eddep41</td>
<td>□</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I felt like a failure</td>
<td>eddep225</td>
<td>□</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I felt unhappy</td>
<td>eddep366</td>
<td>□</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Variables eddep225 and eddep366 added in 2018**

**PROMIS Depression T-Score: deptscore**

### FATIGUE

#### During the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>17.</td>
<td>I feel fatigued</td>
<td>hi7</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
</tr>
<tr>
<td>18.</td>
<td>I have trouble starting things because</td>
<td>an3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.</td>
<td>My sleep quality was</td>
<td>sleep109</td>
<td>□ 5</td>
<td>□ 4</td>
<td>□ 3</td>
</tr>
</tbody>
</table>

### SLEEP DISTURBANCE

#### In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>22.</td>
<td>My sleep was refreshing</td>
<td>sleep116</td>
<td>□ 5</td>
<td>□ 4</td>
<td>□ 3</td>
</tr>
<tr>
<td>23.</td>
<td>I had a problem with my sleep</td>
<td>sleep20</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
</tr>
<tr>
<td>24.</td>
<td>I had difficulty falling asleep</td>
<td>sleep44</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
</tr>
</tbody>
</table>

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

### ABILITY TO PARTICIPATE IN SOCIAL ROLES AND ACTIVITIES
In the past 7 days…

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. I have trouble doing all of my regular leisure activities with others</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
<td>☐</td>
<td>☑️</td>
</tr>
<tr>
<td>26. I have trouble keeping up with my family responsibilities</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
</tr>
<tr>
<td>27. I have trouble doing all of my usual work (include work at home)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
</tr>
<tr>
<td>28. I have trouble keeping in touch with others</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
</tr>
</tbody>
</table>

PROMIS Ability to Participate in Social Roles T-Score: socrolscore

PAIN INTERFERENCE

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. How much did pain interfere with your day to day activities?</td>
<td>☐</td>
<td>☑️</td>
<td>☑️</td>
<td>☑️</td>
<td>☑️</td>
</tr>
<tr>
<td>30. How much did pain interfere with work around the home?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
</tr>
<tr>
<td>31. How much did pain interfere with your ability to participate in social activities?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
</tr>
<tr>
<td>32. How much did pain interfere with your household chores?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑️</td>
</tr>
</tbody>
</table>

PROMIS Pain Interference T-Score: painintscore

Pain Intensity

<table>
<thead>
<tr>
<th>Question</th>
<th>No pain</th>
<th>Worst imaginable pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>33. How would you rate your pain on average?</td>
<td>☐</td>
<td>☑️</td>
</tr>
</tbody>
</table>

Sexual Function & Satisfaction

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How satisfied have you been with your sex life?</td>
<td>☐</td>
<td>☑️</td>
<td>☑️</td>
<td>☑️</td>
<td>☑️</td>
</tr>
<tr>
<td>2. How much pleasure has your sex life given you?</td>
<td>☐</td>
<td>☑️</td>
<td>☑️</td>
<td>☑️</td>
<td>☑️</td>
</tr>
</tbody>
</table>

Sexual Function & Satisfaction added in 2018

Upper Extremity

PROMIS Sexual FS T-Score: fsattscore
Interviewer Instructions: If the participant had a hand burn, please complete the next 4 questions. If the participant did NOT have a hand burn, please move on to NeuroQOL Stigma SF, below.

<table>
<thead>
<tr>
<th>Question</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</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you able to cut your food using eating utensils? pfa20</td>
<td>□ 5</td>
<td>□ 4</td>
<td>□ 3</td>
<td>□ 2</td>
<td>□ 1</td>
</tr>
<tr>
<td>2. Are you able to open a can with a hand can opener? pfa28</td>
<td>□ 5</td>
<td>□ 4</td>
<td>□ 3</td>
<td>□ 2</td>
<td>□ 1</td>
</tr>
<tr>
<td>3. Are you able to button your shirt? pfa54</td>
<td>□ 5</td>
<td>□ 4</td>
<td>□ 3</td>
<td>□ 2</td>
<td>□ 1</td>
</tr>
<tr>
<td>4. Are you able to pick up coins from a table top? pfb21r1</td>
<td>□ 5</td>
<td>□ 4</td>
<td>□ 3</td>
<td>□ 2</td>
<td>□ 1</td>
</tr>
</tbody>
</table>

Upper extremity sections added in 2018

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>Question</th>
<th>Never=1</th>
<th>Rarely=2</th>
<th>Sometimes=3</th>
<th>Often=4</th>
<th>Always=5</th>
<th>88/Refused 99/Unknown</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>
<td>88/Refused 99/Unknown</td>
</tr>
<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>
<td>88/Refused 99/Unknown</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>
<td>88/Refused 99/Unknown</td>
</tr>
<tr>
<td>4. I felt embarrassed about my injury. nqstg16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88/Refused 99/Unknown</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>
<td>88/Refused 99/Unknown</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>
<td>88/Refused 99/Unknown</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>
<td>88/Refused 99/Unknown</td>
</tr>
<tr>
<td>8. Some people acted as though it was my fault I have this injury. nqstg21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88/Refused 99/Unknown</td>
</tr>
</tbody>
</table>

NeuroQOL Stigma SF T-Score: nqstgtscore

PROMIS Upper Extremity T-Score: upextscore
**Burn Specific Health Body Image Sub-Scale:**

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

<table>
<thead>
<tr>
<th>To what extent does each of the following statements describe you?</th>
<th>Extreme(ly)</th>
<th>Quite a bit</th>
<th>Moderate(ly)</th>
<th>A little bit</th>
<th>None (not at all)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BH24. Sometimes, I would like to forget that my appearance has changed. <strong>bshs_24</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>BH25. I feel that my burn is unattractive to others. <strong>bshs_25</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>BH26. My general appearance really bothers me. <strong>bshs_26</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>BH27. The appearance of my scars bothers me. <strong>bshs_27</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

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

**BSHS Body Image:** **bshs_bi**

**CAGE Alcohol Use:**

Now I have a few questions about alcohol and drugs.

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

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

1. Have you felt you needed to **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 crack or heroin; or about prescription drugs like pain killers or stimulants that were not prescribed to you; or chemicals you might have inhaled or 'huffed'. We also want to know if sometimes you took more than you should have of any drugs that have been prescribed to you.”
Interviewer instructions: If the participant states they do not drink after the first question, you can fill in “No” for all four questions and skip to PTSD Checklist, below.

In the past year...(Or, since your last interview, if this is the 6 or 12 month interview)
1. Have you ever felt you needed to Cut down on your drug use? □ Yes (1) □ No (0)

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

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

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

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

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

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

PTSD Checklist:

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

<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 memories, thoughts, or images of your burn injury? pclc_1</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Repeated, disturbing dreams of your burn injury? pclc_2</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Suddenly acting or feeling as if your burn injury were happening again (as if you were reliving it)? pclc_3</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
### PCLC Total Score Variable: ptsdc_tot
### PCLC DSM Criteria Score Variable: ptsdc_dsm

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

#### Currently:
1. Who usually looks after your personal finances, such as banking and paying bills? cia2
   - 1. Yourself alone
   - 2. Yourself and someone else
   - 3. Someone else

2. Shopping ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

3. Shopping for other things ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

4. Shopping for groceries ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

5. Shopping for household items ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

6. Shopping for clothing ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

7. Shopping for personal items ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

8. Shopping for medications ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

9. Shopping for gifts ci3
   - 1. Never
   - 2. 1-4 times
   - 3. 5 or more times

10. Shopping for household supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

11. Shopping for personal supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

12. Shopping for transportation ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

13. Shopping for leisure activities ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

14. Shopping for education ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

15. Shopping for entertainment ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

16. Shopping for household repairs ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

17. Shopping for personal repairs ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

18. Shopping for medical supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

19. Shopping for insurance ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

20. Shopping for utilities ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

21. Shopping for pet supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

22. Shopping for child care ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

23. Shopping for child care supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

24. Shopping for baby supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

25. Shopping for household goods ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

26. Shopping for personal goods ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

27. Shopping for clothing ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

28. Shopping for personal care ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

29. Shopping for home furnishings ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

30. Shopping for household equipment ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

31. Shopping for household cleaning supplies ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

32. Shopping for household repairs ci3
    - 1. Never
    - 2. 1-4 times
    - 3. 5 or more times

33. Shopping for home repairs 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

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. □ Not applicable (no leisure activities)

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

1. □ Yes
2. □ No

**CIQ Social Integration Total Score: ciqsic**

**Satisfaction with Life:**

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

<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: <strong>sl1</strong></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: <strong>sl2</strong></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 <strong>sl3</strong></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 <strong>sl4</strong></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:</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
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=I did not experience this change</th>
<th>1=To a very small degree</th>
<th>2=To a small degree</th>
<th>3=To a moderate degree</th>
<th>4=To a great degree</th>
<th>5=To a very great degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I changed my priorities about what is important in life ptgi_1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. I have a greater appreciation for the value of my own life ptgi_2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. I am able to do better things with my life. ptgi_3</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. I have a better understanding of spiritual matters. ptgi_4</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. I have a greater sense of closeness with others. ptgi_5</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. I established a new path for my life. ptgi_6</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. I know better that I can handle difficulties. ptgi_7</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. I have a stronger religious faith. ptgi_8</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. I’ve discovered that I’m stronger than I thought I was. ptgi_9</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. I learned a great deal about how wonderful people are. ptgi_10</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Post Traumatic Growth Inventory Total Score: ptgitot
DEMOGRAPHICS:

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

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

1. What is your current weight? (lbs) _htfu________ (code 9999 for unknown)
   Added to adult data collection in 2015
2. What is your current height? (feet/inches) _wtfu_______ (code 9999 for unknown)
   Added to adult data collection in 2015
3. Where are you currently living? (Choose only one) resdencfu
   1. ☐ Private residence
   2. ☐ Nursing home
   3. ☐ Adult home
   4. ☐ Correctional institution
   5. ☐ Hotel/motel
   6. ☐ Homeless
   7. ☐ Hospital
   In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data (“institution”) is considered missing in new coding scheme (not enough information in “institution” to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.

4. What is your current zip code? _zipfu________________
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

5. Who are you currently living with? (Choose all that apply)
   Interviewer instructions: Probe if needed to make sure that all people participant is living with are accounted for in their answer.
   1. ☐ Alone livingafu___1
   2. ☐ Spouse/partner/significant other livingafu___2
   3. ☐ Friend livingafu___3
   4. ☐ Parent or step-parent livingafu___4
   5. ☐ Other relative (siblings, grandparents) livingafu___5
   6. ☐ Others, not part of family livingafu___6
   7. ☐ Guardian livingafu___7
   8. ☐ Young children livingafu___8
   9. ☐ Adult children livingafu___9
   88. ☐ Declined to answer/Refused livingafu___88
   99. ☐ Unknown livingafu___99

6. What is your current marital status? (Choose only one) marstatfu
   1. ☐ Married; living common-law or with a partner
   2. ☐ Separated
   3. ☐ Divorced
   4. ☐ Widowed
   5. ☐ Single (not married)
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown

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

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

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

- 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)

8. How many people are in your household? _numhsfup_  
   (Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

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

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

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

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

- 1 - Executive, Administrative, And Managerial; 2 - Professional Specialty; 3 - Technicians And Related Support; 4 - Sales; 5 - Administrative Support Including Clerical; 6 - Private Household; 7 - Protective Service; 8 - Service, Except Protective And Household; 9 - Farming, Forestry, And Fishing; 10 - Precision Production, Craft, And Repair; 11 - Machine Operators, Assemblers, And Inspectors; 12 - Transportation And Material Moving; 13 - Handlers, Equipment Cleaners, Helpers, And Laborers; 14 - Military Occupations; 77 – Not Applicable; 88 – Declined to Answer/Refused; 99 – Unknown
11. What is your current employment status? (Choose only one) `employ_fup`
   1. [ ] Working  *(Interviewer Instructions: continue with next question)*
   2. [ ] Not working (looking for work)
   3. [ ] Not working (not looking for work)
   4. [ ] Homemaker/caregiver
   5. [ ] Volunteer
   6. [ ] Retired
   99. [ ] Unknown

Old variable was named “employfu”.

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

12. Have you received any work accommodations from your employer due to your burn injury? This could include a change in procedure or schedule, a modification to your work site, or assistive equipment. `employacc`
   1. [ ] No, my employer was not asked for accommodations and I did not receive any
   2. [ ] No, my employer was asked for accommodations, but the request was denied
   3. [ ] Yes, my employer was asked for accommodations and I received some or all accommodations asked for
   4. [ ] Yes, my employer provided accommodations without being asked.
   88. [ ] Declined to answer/Refused
   99. [ ] Unknown

New variable added in 2018

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

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

   Entered into the patient status form: returndat

14. About how many hours a week do you work for pay? `hpayfup`____
   777. [ ] Not applicable (not employed)
   888. [ ] Declined to answer/Refused
   999. [ ] Unknown

*Interviewer Instructions: Skip#15 and move on to #16 on the next page if the participant declined to answer the household income question or if the participant is a one person household (fill in income from household question if the participant is a one person household).*

15. Approximately what was your individual income for the past full year? `inccatfup`

   If clarification about currency is needed, say, “these categories are in U.S. dollar amounts.”
1. □ Less than $25,000
2. □ $25,000-$40,999
3. □ $41,000-$55,999
4. □ $56,000-$70,999
5. □ $71,000-$85,999
6. □ $86,000-$100,000
7. □ Greater than $100,000
8. □ Living outside the United States
9. □ Not applicable (no individual income)

16. What is your current school status? \textit{aschoolfu}
   1. □ In School \textit{(Interviewer Instructions: Continue with #17 below if this is a 6, 12, or 24 month follow-up. Skip to #18 if this is a 5, 10, or 15 year follow-up.)}
   2. □ Not in School \textit{(Interviewer Instructions: Skip to #18, below)}
99. □ Unknown

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

17. …is it the same program or a new program as compared with your last interview? \textit{(Or, as compared with before your burn injury, if this is a 6 month follow-up).} \textit{aprogfu}

\textit{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

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

18. If you aren’t working or going to school, why not? \textit{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
99. □ Not applicable (working or going to school)
19. How many years of education have you completed?  
*(Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed. “If you have not graduated from high school, please indicate the number of years spent in school. If you have at least a high school diploma, please indicate the highest degree earned or worked toward post-high school.”) If participant tries to count years rather than degree attained, use the prompt, “In other words, what is the highest level of education you have completed?”). educfup

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

1. ☐ 1 year or less
2. ☐ 2 years
3. ☐ 3 years
4. ☐ 4 years
5. ☐ 5 years
6. ☐ 6 years
7. ☐ 7 years
8. ☐ 8 years
9. ☐ 9 years
10. ☐ 10 years
11. ☐ 11 or 12 years; no diploma
12. ☐ High school diploma
13. ☐ Work towards Associate’s degree, vocational degree, or trade school diploma/certificate
14. ☐ Associate’s degree, vocational degree, or trade school diploma/certificate
15. ☐ Work towards Bachelor’s degree
16. ☐ Bachelor’s degree
17. ☐ Work towards Master’s degree
18. ☐ Master’s degree
19. ☐ Work towards doctorate level degree
20. ☐ Doctoral level degree
21. ☐ Other
22. ☐ Other

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

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

1. ☐ No
2. ☐ Yes
77. ☐ Not applicable

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

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

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

88. ☐ Declined to answer/Refused
99. ☐ Unknown
Interviewer Instructions: If the participant is receiving disability income, continue with #22
22. If yes, are you receiving disability income due to your burn injury?  disincbrn
   1. ☐ Yes, I am receiving disability income due to my burn injury
   2. ☐ No, I am not receiving disability income due to my burn injury
   77. ☐ Not applicable (not receiving disability income)
   99. ☐ Unknown

23. Do you currently have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)?  physprobfup
   1. ☐ Yes
   2. ☐ No
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown

24. Do you currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)?  cogimpfup
   1. ☐ Yes
   2. ☐ No
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown

25. Who is the primary sponsor of your care currently, or who is paying for the majority of your burn care costs? (Choose only one)  pay_fup
   1. ☐ Medicare
   2. ☐ Medicaid (DSHS)
   3. ☐ Private insurance/HMO/PPO/Pre-paid/Managed
   4. ☐ Worker’s compensation (L&I)
   6. ☐ Champus/Tri-Care
   7. ☐ Self-pay or indigent (public support)
   9. ☐ VA
   10. ☐ Other
   11. ☐ Philanthropy (private support or private foundation or Shriners hospital)
   77. ☐ Not applicable (no burn care costs)

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

27. Have you ever served in the military?  milfup
   1. ☐ No
   2. ☐ Yes
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown

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

We’re done with the survey. Thank you very much for your participation in this research study!”
Indicate time survey ended: ____________
Today’s Date: ___ ___ / ___ ___ / _____ 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
   2. ☐ Mail
   3. ☐ Telephone interview
   4. ☐ Online
   5. ☐ Medical record review

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

3. Checklist of forms: mark when each is complete status
   1. ☐ Patient Status Form status___1
   2. ☐ Medical Record Abstraction Form status___2
   3. ☐ Form I status___3

**Interviewer Instructions**: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

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

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

**Introduction script:**

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

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

Child Health Conditions

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

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

Responses for this question are:

<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>Not at all</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To a very small extent</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To a small extent</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To a moderate extent</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To a fairly great extent</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To a great extent</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To a very great extent</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</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>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</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Hearing? chcself2, chcself2a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Learning and understanding? chcself3, chcself3a</td>
<td>Yes</td>
<td>No</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</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Controlling emotions or behavior? chcself5, chcself5a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. with Seizures or epilepsy? chcself6, chcself6a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. involving the Mouth (eg, chewing, swallowing, and drooling)? chcself7, chcself7a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. with Teeth and gums? chcself8, chcself8a</td>
<td>Yes</td>
<td>No</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</td>
<td>No</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</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. with Growth? chcself12, chcself12a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Sleeping? chcself13, chcself13a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. with Repeated infections? chcself14, chcself14a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. with Breathing (eg asthma)? chcself15, chcself15a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcself16, chcself16a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. with other Skin problems (eg eczema)? chcself17, chcself17a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. with the Heart (such as a birth defect)? chcself18, chcself18a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. with Pain? chcself19, chcself19a</td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
19. Do you have any other health problems? □ Yes □ No
If yes, specify problem: ____________________

Pre-Injury History

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

**NIH TB General Life Satisfaction CAT Ages 13-17**
Indicate how much you agree or disagree...

<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

**CIQ Pre-Burn:**

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

**During the 4 weeks before your burn:**
1. Did you take responsibility for personal grooming when asked? cip2_pre
   - 1. □ Often
   - 2. □ Sometimes
   - 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
   - 2. □ 1-4 times
   - 3. □ 5 or more times

3. Leisure activities such as movies, sports, and restaurants. ci4_pre
   - 1. □ Never
   - 2. □ 1-4 times
   - 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
   3. □ Mostly with family members 99. □ Unknown
   4. □ Mostly with friends
   5. □ With a combination of family and friends
   77. □ Not applicable (no leisure activities)

6. Did you have a best friend with whom you confided? ci7_pre
   1. □ Yes 88. □ Declined to answer/Refused
   2. □ No 99. □ Unknown

   CIQ Social Integration Subscale Total Score Pre-Injury: ciqsic_pre

Pain Medication

1. In the month before your burn injury did you take prescription medication for pain on a regular basis? pmed_pre
   1. □ Yes 88. □ Declined to answer/Refused
   2. □ No 99. □ Unknown

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

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

4. Did you receive psychological therapy or counseling in the last 12 months? psychtr
   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)
   - Check only one box.
   - In 2018, the categories were updated to what is seen here. Data that was collected prior to 2018 was merged into this variable and recoded: categories 1, 2, and 3 (house, apartment, and mobile home) were recoded as category 1; 4 in previously collected BMS data ("institution") is considered missing in new coding scheme (not enough information in "institution" to determine which category the data should be moved to); 5 (homeless) moved to 6 (homeless). Previously collected data was archived.
   1. Private residence
   2. Nursing home
   3. Correctional institution
   4. Hotel/motel
   5. Homeless
   6. Hospital

2. What was your zip code at the time of your burn injury? __ __ __ __ __ zip_pre
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)
   Added to data collection forms in 2015.

3. Who were you living with before your burn injury? (Choose all that apply)
   4. Parent or step-parent livinga___4     88. □ Declined to answer/Refused
   5. Other relative (siblings, grandparents) livinga___5
   6. Others, not part of family livinga___6     0 = not checked
   7. Guardian livinga___7     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?
   - Check only one box.
   - 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?
   2. Other medical problems
   4. Emotional/social
   5. Legal/jail
   6. Substance abuse
   7. Personal choice
   8. Other
   88. □ Declined to answer/Refused
   99. □ Unknown

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

7. Before your burn injury, did you have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)?
   1. Yes
   88. □ Declined to answer/Refused
   99. □ Unknown
8. Before your burn injury, were you ever told by a doctor that you had any of the following psychological issues (choose all that apply)?

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

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

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

Pain

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

<table>
<thead>
<tr>
<th>How would you rate your pain on average?</th>
<th>0</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>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Demographics

This is the last section of the survey.

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

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

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

2. What is your ethnicity? ethnicity
   1. □ Hispanic or Latino
   2. □ Not Hispanic or Latino

3. What is your dominant hand? handdom
   1. □ Left
   2. □ Right
   3. □ Ambidextrous
   99. □ Don’t know

1. After your hospital discharge, where will you be living? (Choose only one) dislivsit
   1. □ Private residence
   2. □ Nursing home
   3. □ Correctional institution
   4. □ Hotel/motel
   5. □ Homeless
   6. □ Hospital
   99. □ Don’t know

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

2. Who will you be living with after hospital discharge? (Choose all that apply)
   4. □ Parent or step-parent livhisdis___4
   5. □ Other relative (siblings, grandparents) livhisdis___5
   6. □ Others, not part of family livhisdis___6
   7. □ Guardian livhisdis___7

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

   Interviewer instructions: Ask the question as open-ended, and then mark the appropriate response below.
   1. □ 1 year or less
   2. □ 2 years
   3. □ 3 years
   4. □ 4 years
   5. □ 5 years
   6. □ 6 years
   7. □ 7 years
   8. □ 8 years
   9. □ 9 years
   10. □ 10 years
   11. □ 11 or 12 years; no diploma
   12. □ High school diploma
   66. □ Other
4. 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

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

___________________________________________________________

___________________________________________________________

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

Indicate time survey ended: ________
BMS Pediatric Parent Proxy 0-7 Interview Form I
NewMSID__________

Today's Date: _____/_____/______
(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: ____________

Who is filling out this questionnaire? (Select all that apply)
  1. ⡱ Mother or stepmother proxydis_1
     proxydis_77, not applicable (not proxy)
  2. ⡱ Father or stepfather proxydis_2
  3. ⡱ Guardian proxydis_3
  4. ⡱ Other proxydis_4

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

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

3. Checklist of forms: mark when each is complete status
   1. ⡱ Patient Status Form status_1 0 = not checked
   2. ⡱ Medical Record Abstraction Form status_2 1 = checked
   3. ⡱ Form I status_4

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

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

All information will be kept confidential.

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

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

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

<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>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>
<td></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></td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td></td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Learning and understanding? chcprox3, chcprox4</td>
<td></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></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></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></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></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></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></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></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></td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. Sleeping? chcprox12, chcprox12a</td>
<td></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></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></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></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></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, chcprox17a</td>
<td></td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>18. with Pain? chcprox18, chcprox18a</td>
<td></td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

19. Does your child have any other health problems? chcprox19 | ☑ Yes! ☐ No
If yes, specify problem: chcprox19ot (text field)  
88. ☐ Declined to answer/Refused
99. ☐ Unknown
Pre-Injury History

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

Pre-Injury Demographics

1. Before your child’s burn injury, where was he/she living? (Choose only one) resdencprx
   1. □ Private residence
   2. □ Nursing home
   4. □ Correctional institution
   5. □ Hotel/motel
   6. □ Homeless
   7. □ Hospital

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

2. What was your child’s zip code at the time of his/her burn injury? __ __ __ __ __ zip_pre
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

Added to data collection forms in 2015.

3. Who was your child living with before his/her burn injury? (Choose all that apply)
   4. □ Parent or step-parent livingaprx_4 0 = checked
   5. □ Other relative (siblings, grandparents) livingaprx_5 1 = not checked
   6. □ Others, not part of family livingaprx_6 88. □ Declined to answer/Refused livingaprx_88

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

4. Was your child enrolled in school at the time of his/her burn injury? (If yes) Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group? aschoolprx
   1. □ In school/age or above age appropriate
   2. □ Not in school
   3. □ In school/below age appropriate

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

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

5. If your child was not enrolled in school at the time of his/her burn injury, why not? whynotprx
   0. □ Not school age
   2. □ Other medical problems
   4. □ Emotional/social
   5. □ Legal/jail
   6. □ Substance abuse
   7. □ Personal choice
   8. □ Other
6. Before his/her burn injury, did your child have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? physprobpreprx
   1. □ Yes
   2. □ No
   88. □ Declined to answer/Refused
   99. □ Unknown

7. Before his/her burn injury, did your child have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? cogimppreprx
   1. □ Yes
   2. □ No
   88. □ Declined to answer/Refused
   99. □ Unknown

8. Before his/her burn injury, was your child ever told by a doctor that he/she had any of the following psychological issues (choose all that apply)? psychlistprx
   1. □ Depression
   2. □ Bipolar disorder
   3. □ Anxiety
   4. □ Post-Traumatic Stress Disorder (PTSD)
   5. □ Schizophrenia/psychotic disorder
   6. □ Other, please explain: ____________________

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

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

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

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

   These questions added with new forms in December 2015.

   4. Did your child receive psychological therapy or counseling in the last 12 months? psychtherprx
      1. □ Yes
      2. □ No
      88. □ Declined to answer/Refused
      99. □ Unknown
Demographics

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

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

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

2. What is your child’s ethnicity? ethnicityprx
   1. [ ] Hispanic or Latino
   2. [ ] Not Hispanic or Latino

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

3. What is your child’s dominant hand? handdomprx
   1. [ ] Left
   2. [ ] Right
   3. [ ] Ambidextrous
   99. [ ] Don’t know

4. After your child’s hospital discharge, where will he/she be living? (Choose only one) dislivsitprx
   1. [ ] Private residence
   2. [ ] Nursing home
   4. [ ] Correctional institution
   5. [ ] Hotel/motel
   6. [ ] Homeless
   7. [ ] Hospital

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

2. Who will your child be living with after hospital discharge? (Choose all that apply)
   4. [ ] Parent or step-parent livingaprx__4
   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.

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

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

- 0. Preschool completed
- 1. 1 year or less
- 2. 2 years
- 3. 3 years
- 77. Not applicable (child is too young for school)

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

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

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

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

5. How many people are in your household? **numhspreprx**

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

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

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

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

**Indicate time survey ended: ___________**
Interviewer instructions: If the child is between 3 and 7 years old, continue with the General Life Satisfaction section, below.

NIH Toolbox General Life Satisfaction

<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. papxy066pre</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. My child’s life was just right. papxy067pre</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. My child had a good life. 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. papxy071pre</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: __________
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric 8-12 Interview Form II
NewMSID________________

Today's Date: ______/_____/______
(NO1E: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: ________

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

1. Follow-up period follow_up
   1. ☐ 6-month follow-up
   2. ☐ 12-month follow-up
   3. ☐ 24-month follow-up
   4. ☐ 5 year follow-up
   5. ☐ 10 year follow-up

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

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

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

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

Previous variable was called “admin_2”.

4. What is the status of this follow-up assessment? (Choose only one) lostfolo
   1. ☐ Some or all assessment done
   2. ☐ Death due to burn related complications
   3. ☐ Death due to non-burn related complications
   4. ☐ Unable to locate
   5. ☐ Refused this assessment
   6. ☐ Unable to test/med comp/incapable of responding
   7. ☐ Failed to respond
   8. ☐ Did not consent to future assessment/withdrew
   9. ☐ Incarcerated
   10. ☐ Still in hospital (not discharged yet)
   11. ☐ Unable to travel for assessment Option 14 added with new forms in 2015
   12. ☐ Death (unknown causes) (Interviewer Instructions: Update date and cause of death on Patient Status Form) Option 15 added with new forms in 2018
Interviewer Instructions: Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant. Have the updated Patient Status form with you to help with the interview.

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

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

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

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

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

We’re going to get started with the survey. Please let me know at any time if you have any questions.
Body Image
The following questions ask about your appearance:

<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. bodyim_4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Body Image Self-Report Total Score: bodyim_tot_self

CPSS – Part I:
I’m going to read a list of problems that kids sometimes have after experiencing an upsetting event. I will read each one carefully to you and then tell me the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.

<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 cpss_1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Having bad dreams or nightmares 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 (hearing something or seeing a picture about it and feeling as if I am there again) 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) 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) 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 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 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 cpss_8</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9. Having much less interest or doing things you used to do \text{cpss}\_9

10. Not feeling close to people around you \text{cpss}\_10

11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) \text{cpss}\_11

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) \text{cpss}\_12

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

13. Having trouble falling or staying asleep \text{cpss}\_13

14. Feeling irritable or having fits of anger \text{cpss}\_14

15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class) \text{cpss}\_15

16. Being overly careful (for example, checking to see who is around you and what is around you) \text{cpss}\_16

17. Being jumpy or easily startled (for example, when someone walks up behind you) \text{cpss}\_17

CPSS Total Score Variable: \text{cpss}\_tot\_score

**PROMIS Anger**

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 felt mad \text{pr206r1}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt upset \text{pr714r1}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I felt fed up \text{pr5045r1}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I was so angry I felt like throwing something \text{pr2319ar1}</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 \text{pr2581r1}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PROMIS Anger Total Score Pediatric: \text{angtscore}\_ped

**PROMIS 25**

**Physical function mobility**

In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>0=with no trouble</th>
<th>1=with a little trouble</th>
<th>2= With some trouble</th>
<th>3= With a lot of trouble</th>
<th>4=Not able to do</th>
</tr>
</thead>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

### BMS Pediatric 8-12 Interview Form II

<table>
<thead>
<tr>
<th>NewMSID_________________________</th>
<th>88 / 99</th>
</tr>
</thead>
</table>

1. I could do sports and exercise that other kids my age could do pr235r1
2. I could get up from the floor pr4124r1
3. I could walk up stairs without holding on to anything pr2707r2
4. I have been physically able to do the activities I enjoy most pr5023r1

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

### Anxiety

In the past 7 days...

<table>
<thead>
<tr>
<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>
</tr>
<tr>
<td>2. I felt nervous pr713r1</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>
</tr>
<tr>
<td>4. I worried when I was at home pr3459br1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

### Depressive Symptoms

In the past 7 days...

<table>
<thead>
<tr>
<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>
</tr>
<tr>
<td>2. I felt lonely pr711r1</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>
</tr>
<tr>
<td>4. It was hard for me to have fun pr3952ar2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

### Fatigue

In the past 7 days...

<table>
<thead>
<tr>
<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. Being tired made it hard for me to keep up with my schoolwork pr4239ar2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I got tired easily pr2876r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I was too tired to do sports or exercise pr4241r2</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 8-12 Interview Form II**

NewMSID

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PROMIS-25 Fatigue T-Score: fattscore_ped</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I was too tired to enjoy the things I like to do</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
</tbody>
</table>

**Peer relationships**

In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt accepted by other kids my age</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
<tr>
<td>2. I was able to count on my friends</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
<tr>
<td>3. My friends and I helped each other out</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
<tr>
<td>4. Other kids wanted to be my friend</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
</tbody>
</table>

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

**Pain Interference**

In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had trouble sleeping when I had pain</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
<tr>
<td>2. It was hard for me to pay attention when I had pain</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
<tr>
<td>3. It was hard for me to run when I had pain</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
<tr>
<td>4. It was hard for me to walk one block when I had pain</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
</tbody>
</table>

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

**Pain Intensity**

In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>How bad was your pain on average?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My life is going well</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>88/99</td>
</tr>
</tbody>
</table>

Declined to answer/Refused

Unknown
2. My life is just right pa067
3. I have a good life pa070
4. I have what I want in life pa071

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

**BMS-Itch (based on PROMIS pain interference and modified for BMS)**
In the past 7 days...

<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>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had trouble sleeping when I was itching bmsitch_1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt angry when I was itching bmsitch_2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I had trouble doing schoolwork when I was itching bmsitch_3</td>
<td></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 bmsitch_4</td>
<td></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 bmsitch_5</td>
<td></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 know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I learned how nice and helpful some people can be. ptgic_1</td>
<td></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. ptgic_2</td>
<td></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. ptgic_3</td>
<td></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. ptgic_4</td>
<td></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. ptgic_5</td>
<td></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. ptgic_6</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.

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Options</th>
<th>NewMSID</th>
<th>88/Refused</th>
<th>88/Refused</th>
<th>88/Refused</th>
<th>88/Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>I now have a chance to do some things I couldn’t do before. <em>ptgic_7</em></td>
<td></td>
<td></td>
<td>88/Refused</td>
<td>88/Refused</td>
<td>88/Refused</td>
<td>88/Refused</td>
</tr>
<tr>
<td>8</td>
<td>My faith (belief) in God is stronger than it was before. <em>ptgic_8</em></td>
<td></td>
<td></td>
<td>88/Refused</td>
<td>88/Refused</td>
<td>88/Refused</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. <em>ptgic_9</em></td>
<td></td>
<td></td>
<td>88/Refused</td>
<td>88/Refused</td>
<td>88/Refused</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. <em>ptgic_10</em></td>
<td></td>
<td></td>
<td>88/Refused</td>
<td>88/Refused</td>
<td>88/Refused</td>
<td>88/Refused</td>
</tr>
</tbody>
</table>

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

Is there anything else you would like to tell us? __________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

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

*Indicate time survey ended: ____________*
Today’s Date: ____/____/____
(NOTE: FIRST TWO PAGES ARE FOR RESEARCH STAFF USE ONLY)

Indicate time survey started: ____________

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

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

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

3. Checklist of forms: mark when each is complete status
   1. □ Patient Status Form status__1
   2. □ Medical Record Abstraction Form status__2 0 = not checked
   3. □ Form I status__4 1 = checked

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

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

Responses for this question are:

- 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>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? chcprox1, chcprox1a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. Learning and understanding? chcprox3, chcprox3a</td>
<td>☐ Yes ☐ No</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)? chcprox4, chcprox4a</td>
<td>☐ Yes ☐ No</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? chcprox5, chcprox5a</td>
<td>☐ Yes ☐ No</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? chcprox6, chcprox6a</td>
<td>☐ Yes ☐ No</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 ☐ No</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? chcprox8, chcprox8a</td>
<td>☐ Yes ☐ No</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)? chcprox9, chcprox9a</td>
<td>☐ Yes ☐ No</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? chcprox10, chcprox10a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>11. with Growth? chcprox11, chcprox11a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>12. Sleeping? chcprox12, chcprox12a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>13. with Repeated infections? chcprox13, chcself13a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>14. with Breathing (eg asthma)? chcprox14, chcprox14a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>16. with other Skin problems (eg eczema)? chcprox16, chcprox16a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>17. with the Heart (such as a birth defect)? chcprox17, chcprox17a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
<tr>
<td>18. with Pain? chcprox18, chcprox18a</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

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

If yes, specify problem: chcprox19ot (text field)

---

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

---
Pre-Injury History

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

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

<table>
<thead>
<tr>
<th>In the four weeks before my child’s burn...</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>papxy066pre</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>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>
<tr>
<td>papxy071pre</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Pre-Injury Demographics
1. Before your child’s burn injury, where was he/she living? (Choose only one) resdencprx
   1. ☐ Private residence
   2. ☐ Nursing home
   4. ☐ Correctional institution
   5. ☐ Hotel/motel
   6. ☐ Homeless
   7. ☐ Hospital

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

2. What was your child’s zip code at the time of his/her burn injury? ___ ___ ___ ___ zipprx_pre
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

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

   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?  
   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?  
   1. □ Other medical problems  
   2. □ Emotional/social  
   3. □ Legal/jail  
   4. □ Substance abuse  
   5. □ Personal choice  
   6. □ 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)?  
   1. □ Yes  
   2. □ No

7. Before the burn, did your child have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)?
   1. □ Yes  
   2. □ No

8. Before his/her burn injury, was your child ever told by a doctor that he/she had any of the following psychological issues (choose all that apply)?
   1. □ Depression  
   2. □ Bipolar disorder  
   3. □ Anxiety  
   4. □ Post-Traumatic Stress Disorder (PTSD)  
   5. □ Schizophrenia/psychotic disorder  
   6. □ Other, please explain: __________

   **Pain Medication**
   1. In the month before your child’s burn injury did he/she take prescription medication for pain on a regular basis?  
      1. □ Yes  
      2. □ No
   2. In the past 12 months, did your child take medication for being, worried, tense, or anxious?  
      1. □ Yes  
      2. □ No
3. In the past 12 months, did your child take medication for being sad, empty, or depressed?  
\textit{smedprx\_pre}  
1. ☐ Yes  
2. ☐ No  
  
88. ☐ Declined to answer/Refused  
99. ☐ Unknown

4. Did your child receive psychological therapy or counseling in the last 12 months?  
\textit{psychtherprx}  
1. ☐ Yes  
2. ☐ No  
  
88. ☐ Declined to answer/Refused  
99. ☐ Unknown

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

1. What is your child’s racial group?  
\textit{raceprx}  
1. ☐ Black or African-American  
2. ☐ Asian  
3. ☐ Caucasian (white)  
4. ☐ American Indian/Alaskan Native  
5. ☐ Native Hawaiian or Other Pacific Islander  
6. ☐ More than one race  
7. ☐ Other (please specify):________________________________________

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

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

2. What is your child’s ethnicity?  
\textit{ethnicityprx}  
1. ☐ Hispanic or Latino  
2. ☐ Not Hispanic or Latino

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

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

3. What is your child’s dominant hand?  
\textit{handdomprx}  
1. ☐ Left  
2. ☐ Right  
3. ☐ Ambidextrous  
99. ☐ Don’t know

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

---

1. After your child’s hospital discharge, where will he/she be living? (Choose only one)  
\textit{dislivsitprx}  
1. ☐ Private residence  
2. ☐ Nursing home  
4. ☐ Correctional institution  

88. ☐ Declined to answer/Refused  
99. ☐ Unknown
5. □ Hotel/motel
6. □ Homeless
7. □ Hospital

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

2. Who will your child be living with after hospital discharge? (Choose all that apply)
4. □ Parent or step-parent livingaprx___4
5. □ Other relative (siblings, grandparents) livingaprx___5
6. □ Others, not part of family livingaprx___6 88. □ Declined to answer/Refused livingaprx___88

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

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

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

1. □ 1 year or less
2. □ 2 years
3. □ 3 years
4. □ 4 years
5. □ 5 years
6. □ 6 years
7. □ 7 years
8. □ 8 years
9. □ 9 years
10. □ 10 years
11. □ 11 or 12 years; no diploma
12. □ High school diploma
66. □ Other
88. □ Declined to answer/Refused
99. □ Unknown

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

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

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

hincatpreprx

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

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

6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply) \_disincdisprx\_ 
   1. My child is not receiving disability income 
   2. Social Security Disability 
   3. Private long term insurance disability income 
   4. Supplemental security income (SSI) 
   5. Worker’s compensation 
   6. Other \_disincdisopr\_ 

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

Is there anything else you would like to tell us? 

_________________________________________________________________________

_________________________________________________________________________

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

**Indicate time survey ended:** __________

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

**CIQ Pre:**

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

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

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

1: Did your child take personal responsibility for grooming when asked? \_cip2prx_pre\_ 
   1. Often 
   2. Sometimes 
   3. Never 

   88. Declined to answer/Refused 
   99. Unknown 

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

**BMS Pediatric Parent Proxy 8-17 Interview Form**
NewMSID________

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

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

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

**During the 4 weeks before your child’s burn:**
5: When your child participated in leisure activities did he/she usually do this alone or with others?
- 1. □ Mostly alone
- 3. □ Mostly with family members
- 4. □ Mostly with friends who do not have burn injuries
- 5. □ With a combination of family and friends
- 77. □ Not applicable (no leisure activities)

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

CIQ Social Integration Proxy Total Score: ciqsicprx_pre

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

__________________________________________________________

__________________________________________________________

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

*Indicate time survey ended: ____________
Today's Date: ___ ___ / ___ ___ / ___ ___

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

Indicate time survey started: __________

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

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

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

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

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

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

Previous variable was called “admin_2”.

4. What is the status of this follow-up assessment? (Choose only one) lostfolo
   1. ☐ Some or all assessment done
   2. ☐ Death due to burn related complications
   3. ☐ Death due to non-burn related complications
   4. ☐ Unable to locate
   5. ☐ Refused this assessment
   6. ☐ Unable to test/med comp/incapable of responding
   7. ☐ Failed to respond
   8. ☐ Did not consent to future assessment/withdrew
   9. ☐ Incarcerated
   10. ☐ Still in hospital (not discharged yet)
   11. ☐ Unable to travel for assessment Option 14 added with new forms in 2015
   12. ☐ Death (unknown causes) (Interviewer Instructions: Update date and cause of death on Patient Status Form) Option 15 added with new forms in 2018
**Interviewer Instructions:** Instructions to the interviewer appear throughout the survey in Times New Roman font and italics, and scripts to read aloud to the participants appear in Arial font, non-italics. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant. Have the updated Patient Status form with you to help with the interview.

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

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

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

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

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

We’re going to get started with the survey. Please let me know at any time if you have any questions.
**Burn Injury Follow-up**

First I have some questions related to your burn injury…

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

*Added in 2015*

2. Since the last interview, have you received any of the following services at home or outpatient? *(Choose all that apply)*
   *If clarification is needed: Examples of occupational therapy include helping with adjusting to a school environment after injury. Examples of physical therapy include range of motion and walking exercises.*

   - [ ] No services (Interviewer Instructions: skip to #6, surgery item, on page 4) services___1
   - [ ] Occupational therapy services___2
   - [ ] Physical therapy services___3 88. [ ] Declined to answer/Refused
   - [ ] Speech language pathology services___4 99. [ ] Unknown
   - [ ] Social work services___5
   - [ ] Psychological services or child life services services___6 0 = not checked
   - [ ] Vocational services services___7 1 = checked

*Added in 2015*

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

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

3. How many sessions of occupational and/or physical therapy have you had in the past 4 weeks? numserv
   - [ ] One 88. [ ] Declined to answer/Refused
   - [ ] 2-4 99. [ ] Unknown
   - [ ] 5-10
   - [ ] More than 10
   77. [ ] No PT/OT (skip to #6, surgery item, on page 4)

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

4. This clinical burn center? ther_brn_cntr 88. [ ] Declined to answer/Refused
   - [ ] Yes 99. [ ] Unknown
   - [ ] No
   77. [ ] Not applicable (no OT/PT received)

*New coding for 77/88/99 added in 2015*

5. Other facility? ther_otr 88. [ ] Declined to answer/Refused
   - [ ] Yes 99. [ ] Unknown
   - [ ] No
   77. [ ] Not applicable (no OT/PT received)

*New coding for 77/88/99 added in 2015*
6. Since your last interview [provide date], have you had any burn related surgeries(such as surgeries for open wounds or scar management)? surgery_fu
1. Yes
2. No (Interviewer Instructions: skip to Child Health Conditions on page x) 88. □ Declined to answer/Refused
99. □ Don't know (Interviewer Instructions: skip to Child Health Conditions on page x) 88. □ Declined to answer/Refused

New coding for 88/99 added in 2015

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

7. Have you had any burn-related surgeries outside of [name the BMS center]? surgout
1. Yes
2. No
99. □ Don’t know

Added in 2015

Child Health Conditions

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

Responses for this question are:

<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>

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

<table>
<thead>
<tr>
<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>□1Yes □0No</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Hearing? chcself2, chcself2a</td>
<td>□1Yes □0No</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Learning and understanding? chcself3, chcself3a</td>
<td>□1Yes □0No</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>□1Yes □0No</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>□1Yes □0No</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>□1Yes □0No</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)? chcself7, chcself7a</td>
<td>□1Yes □0No</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>□1Yes □0No</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>□1Yes □0No</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>□1Yes □0No</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>11. with Growth? chcself11, chcself11a</td>
<td>□1Yes □0No</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td></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>
<tr>
<td>---</td>
<td>------------</td>
<td>------------------------</td>
<td>-------------------</td>
<td>----------------------</td>
<td>------------------------</td>
<td>-------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>1.</td>
<td>Do you have problems…</td>
<td>Problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12.</td>
<td>Sleeping? chcself12, chcself12a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13.</td>
<td>with Repeated infections? chcself13, chcself13a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14.</td>
<td>with Breathing (eg asthma)? chcself14, chcself14a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>15.</td>
<td>with Chronic open skin areas (eg chronic open wounds)? chcself15, chcself15a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16.</td>
<td>with other Skin problems (eg eczema)? chcself16, chcself16a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17.</td>
<td>with the Heart (such as a birth defect)? chcself17, chcself17a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>18.</td>
<td>with Pain? chcself18, chcself18a</td>
<td></td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

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

**Pain Medication**

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

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

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

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

5. Since your last research study questionnaire, have you received psychological therapy or counseling due to your burn injury? psychther
   1. ☐ Yes | 88. ☐ Declined to answer/Refused
   2. ☐ No | 99. ☐ Unknown
**Body Image**
The following questions ask about your appearance:

<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>Problem</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 (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>
<tr>
<td>cpss_10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy) cpss_11

12. Feeling as if your future plans or hopes will not come true (for example, you will not have a job or getting married or having kids) cpss_12

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.

13. Having trouble falling or staying asleep cpss_13

14. Feeling irritable or having fits of anger cpss_14

15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class) cpss_15

16. Being overly careful (for example, checking to see who is around you and what is around you) cpss_16

17. Being jumpy or easily startled (for example, when someone walks up behind you) cpss_17

**CPSS Total Score Variable: cpss_tot_score**

**PROMIS Anger**

<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. 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>
</tbody>
</table>

**PROMIS Anger Total Score Pediatric: angtscore_ped**

**PROMIS 25**

**Physical function mobility**

<table>
<thead>
<tr>
<th>Question</th>
<th>0=with no trouble</th>
<th>1=with a little trouble</th>
<th>2=With some trouble</th>
<th>3=With a lot of trouble</th>
<th>4=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>2. I could get up from the floor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. I could walk up stairs without holding on to anything pr2707r2
4. I have been physically able to do the activities I enjoy most pr5023r1

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

### 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>

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

### 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 pr3952r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

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

### 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>
<tbody>
<tr>
<td>1. Being tired made it hard for me to keep up with my schoolwork pr4239ar2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. I got tired easily pr2876r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. I was too tired to do sports or exercise pr4241r2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. I was too tired to enjoy the things I like to do pr4196r1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**PROMIS Fatigue T-Score Variable: fattscore_ped**
### Peer relationships

**In the past 7 days...**

<table>
<thead>
<tr>
<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 accepted by other kids my age pr5018r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I was able to count on my friends pr5058r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My friends and I helped each other out pr5055r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Other kids wanted to be my friend pr233r2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PROMIS Peer Relationships T-Score Variable: peertscore_ped

### Pain Interference

**In the past 7 days...**

<table>
<thead>
<tr>
<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 had pain pr3793r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. It was hard for me to pay attention when I had pain pr9004</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. It was hard for me to run when I had pain pr2045r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. It was hard for me to walk one block when I had pain pr2049r1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PROMIS Pain Interference T-Score Variable: painintscore_ped

### Pain Intensity

**In the past 7 days...**

How bad was your pain on average? pr9033r1

<table>
<thead>
<tr>
<th>0-No pain</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>
<th>9</th>
<th>10-Worst pain you can think of</th>
</tr>
</thead>
<tbody>
<tr>
<td>88.</td>
<td>Declined to answer/Refused</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>99.</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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
CIQ:

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

Currently:
1. Did you take responsibility for personal grooming when asked? cip2
   1. □ Often
   2. □ Sometimes
   3. □ Never

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

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

2: Shopping ci3
   1. □ Never
   2. □ 1-4 times
   3. □ 5 or more times

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

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

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

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

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

5: When you participate in leisure activities do you usually do this alone or with others? ci6
   1. □ Mostly alone
   2. □ Mostly with friends who have burn injuries
   3. □ Mostly with family members
   4. □ Mostly with friends who do not have burn injuries
   5. □ With a combination of family and friends
   77. □ Not applicable (no leisure activities)

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

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

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

CIQ Social Integration Total Score: ciqsic

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

<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>
**BMS Pediatric 13-17 Interview 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 had trouble sleeping when I was itching <strong>bmsitch_1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt angry when I was itching <strong>bmsitch_2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I had trouble doing schoolwork when I was itching <strong>bmsitch_3</strong></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 <strong>bmsitch_4</strong></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 <strong>bmsitch_5</strong></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 know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I learned how nice and helpful some people can be. <strong>ptgic_1</strong></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. <strong>ptgic_2</strong></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. <strong>ptgic_3</strong></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. <strong>ptgic_4</strong></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. <strong>ptgic_5</strong></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. <strong>ptgic_6</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I now have a chance to do some things I couldn’t do before. <strong>ptgic_7</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. My faith (belief) in God is stronger than it was before. <strong>ptgic_8</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I have learned that I can deal with more things than I thought I could before. <strong>ptgic_9</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I have new ideas about how I want things to be when I grow up. <strong>ptgic_10</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PTGI Child Version Total Score Variable: ptgictot**
DEMOGRAPHICS

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

Interviewer instructions: Record participant’s weight and height in pounds and feet/inches. Enter into database in kg and cm

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

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

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

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

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

4. What is your current zip code? __________
   
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

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

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

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

   88. Declined to answer/Refused
   99. Unknown

6. What is your current school status?

   1. In School (Interviewer Instructions: Continue with #7 below if this is a 6, 12, or 24 month follow-up. Skip to #10 on the next page if this is a 5, 10, or 15 year follow-up.)
   2. Not in School (Interviewer Instructions: Skip to #8 below)
   99. Unknown

   Interviewer Instructions: If in school and this is a 6, 12, or 24 month follow-up, ask…
   7. …is it the same program or a new program as compared with your last interview? (Or, as compared with before your burn injury, if this is a 6 month follow-up).

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

   1. Same program full time
   2. Same program part time
   3. New program full time
   4. New program part time
   5. Did not resume school

   88. Declined to answer/Refused
   99. Unknown
6. □ Returned to individual program, home school
7. □ Not in school

**Interviewer instructions:** Skip #8 and move on to #10, below, if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.

8. What was your first date to return to school since the injury? (Please take your best guess if you don’t know the exact date) : _____/_____/_______

**Entered into the patient status form: returndat**

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

9. If you aren’t going to school, why not? **whynotfu**
   1. □ Burn related
   2. □ Other medical problems
   3. □ Emotional/social
   4. □ Legal/jail
   5. □ Substance abuse
   6. □ Personal choice
   7. □ Other
   77. □ Not applicable (going to school)

10. How many years of education have you completed? **(Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, “If you have not graduated from high school, please indicate the number of years spent in school.”) If participant tries to count years rather than degree attained, use the prompt, “In other words, what is the highest level of education you have completed?”** **educfup**

   **Interviewer Instructions:** Ask the question as open-ended, and then mark the appropriate response.
   
   1. □ 1 year or less
   2. □ 2 years
   3. □ 3 years
   4. □ 4 years
   5. □ 5 years
   6. □ 6 years
   7. □ 7 years
   8. □ 8 years
   9. □ 9 years
   10. □ 10 years
   11. □ 11 or 12 years; no diploma
   12. □ High school diploma
   66. □ Other

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

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

   1. □ I am not receiving disability income **(Interviewer Instructions: skip to #13 if the participant is not receiving disability income)**
   2. □ Social Security Disability

88. □ Declined to answer/Refused
99. □ Unknown
3. □ Private long term insurance disability income
4. □ Supplemental security income (SSI)
5. □ Worker’s compensation
6. □ Other ___________ disincfupo

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

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

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

14. Do you currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? cogimpfup
   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: ____________
Today's Date: ___ ___ / ___ ___ / ___ ___

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

Indicate time survey started: __________

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

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

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

1. Follow-up period follow_up
   1. □ 6-month follow-up
   2. □ 12 month follow-up
   3. □ 24 month follow-up
   4. □ 5 year follow-up

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

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

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

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

Previous variable was called “admin_2”.

4. What is the status of this follow-up assessment? (Choose only one) lostfolo
   1. □ Some or all assessment done
   2. □ Death due to burn related complications
   3. □ Death due to non-burn related complications
   4. □ Unable to locate
   5. □ Refused this assessment
   6. □ Unable to test/med comp/incapable of responding
   7. □ Failed to respond
   8. □ Did not consent to future assessment/withdrew
   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
15. □ Death (unknown causes) *(Interviewer Instructions: Update date and cause of death on Patient Status Form)* Option 15 added with new forms in 2018

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

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

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

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

Thank you for continuing to participate in our study of young people with burn injuries. Like our previous interviews, I’ll be asking questions about your child’s burn injury and other questions about him/her and people around him/her. Your answers will help us understand the experiences of all people with burn injury. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential. If you are unsure how to answer a question, please give the answer that fits your child best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.”

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

First I have some questions related to your child’s burn injury…

1. Since your last interview, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? Interviewer Instructions: The parent can choose N/A if their child is under the age of 5 or too young to discuss problems with other burn survivors. peersupprx
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable
   99. ☐ Don’t know

2. Since the last interview, has your child received any of the following services at home or outpatient? (Choose all that apply)
   If clarification needed: Examples of occupational therapy include helping with adjusting to a school environment after injury. Examples of physical therapy include range of motion and walking exercises.
   1. ☐ No services (Interviewer Instructions: skip to #6, surgery item, on the next page) servicesprx___1
   2. ☐ Occupational therapy servicesprx___2 88. ☐ Declined to answer/Refused servicesprx___88
   4. ☐ Speech language pathology servicesprx___4 0 = not checked
   5. ☐ Social work servicesprx___5 1 = checked
   6. ☐ Psychological services servicesprx___6
   7. ☐ Vocational services or child life services servicesprx___7

Added in 2015

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

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

3. How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? numtherprx
   1. ☐ One
   2. ☐ 2-4
   3. ☐ 5-10
   4. ☐ More than 10
   77. ☐ No PT/OT (skip to #6, surgery item, on the next page)

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

4. This clinical burn center? ther_brn_ctrprx 88. ☐ Declined to answer/Refused
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable (no OT/PT received)
5. Other facility? ther.otrprx
   1. ☐ Yes
   2. ☐ No
   77. ☐ Not applicable (no OT/PT received)

6. Since your last interview [provide date], has your child had any burn related surgeries (such as surgeries for open wounds or scar management)? surgery_fuprx
   1. ☐ Yes
   2. ☐ No
   88. ☐ Declined to answer/Refused
   99. ☐ Don't know (Interviewer Instructions: skip to Child Health Conditions, below)

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

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

7. Has your child had any burn-related surgeries outside of [name the BMS center]? surgoutprx
   1. ☐ Yes
   2. ☐ No
   88. ☐ Declined to answer/Refused
   99. ☐ Don't know (Interviewer Instructions: skip to Child Health Conditions, below)

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>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>To a very small extent</td>
</tr>
<tr>
<td>3</td>
<td>To a small extent</td>
</tr>
<tr>
<td>4</td>
<td>To a moderate extent</td>
</tr>
<tr>
<td>5</td>
<td>To a fairly great extent</td>
</tr>
<tr>
<td>6</td>
<td>To a great extent</td>
</tr>
<tr>
<td>7</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>☐1 Yes ☐0 No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Hearing? chcprox2, chcprox2a</td>
<td>☐1 Yes ☐0 No</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>☐1 Yes ☐0 No</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>☐1 Yes ☐0 No</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>☐1 Yes ☐0 No</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>☐1 Yes ☐0 No</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>☐1 Yes ☐0 No</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
### BMS Pediatric Proxy 0-7 Interview Form II

NewMSID____________

<table>
<thead>
<tr>
<th>8. with Teeth and gums? chcprox8, chcprox8a</th>
<th>□ Yes □ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. with Digestion (eg reflux, vomiting, or constipation)? chcprox9, chcprox9a</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>10. with Type 1 or Type 2 diabetes? chcprox10, chcprox10a</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>11. with Growth? chcprox11, chcprox11a</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>12. Sleeping? chcprox12, chcprox12a</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

Does your child have problems… Problem? 1 2 3 4 5 6 7

| 13. with Repeated infections? chcprox13, chcprox13a | □ Yes □ No |
| 14. with Breathing (eg asthma)? chcprox14, chcprox14a | □ Yes □ No |
| 15. with Chronic open skin areas (eg chronic open wounds)? chcprox15, chcprox15a | □ Yes □ No |
| 16. with other Skin problems (eg eczema)? chcprox16, chcprox16a | □ Yes □ No |
| 17. with the Heart (such as a birth defect)? chcprox17, chcprox17a | □ Yes □ No |
| 18. with Pain? chcprox18, chcprox18a | □ Yes □ No |

19. Does your child have any other health problems? chcprox19 □ Yes □ No
   If yes, specify problem: chcprox19ot (text field) 88. □ Declined to answer/Refused
   99. □ Unknown

### Pain and Itch

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

<table>
<thead>
<tr>
<th></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 bmstitch</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Pain Medication

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

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

3. In the **past 12 months**, did your child take medication for being, worried, tense, or anxious? wmedprx
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

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

NewMSID____________

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

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

5. Since your last interview, has your child received psychological therapy or counseling due to his/her burn injury? psychtherprx
   1. ☐ Yes 88. ☐ Declined to answer/Refused
   2. ☐ No 99. ☐ Unknown

Previous variable, psych, used this wording:

FT27. Since your last follow-up, have you received psychological or peer support therapy for your burn? New variables, splitting psych into two questions, added in 2015

**DEMOGRAPHICS**

Next I have some general questions about your child.

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

1. What is your child’s current weight? (lbs) _wtfuprx___ (code 9999 for unknown)

2. What is your child’s current height? (feet/inches) _htfuprx_ (code 9999 for unknown)

3. Where is your child currently living? (Choose only one) resdencfuprx
   1. ☐ Private residence
   2. ☐ Nursing home
   4. ☐ Correctional institution
   5. ☐ Hotel/motel
   6. ☐ Homeless
   7. ☐ Hospital

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

4. What is your child’s current zip code? ___ zipfuprx ________
   (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

5. Who is your child currently living with? (Choose all that apply)
   Interviewer instructions: Probe if needed to make sure that all people child is living with are accounted for in the answer.
   4. ☐ Parent or step-parent livingafu___4
   5. ☐ Other relative (siblings, grandparents) livingafu__5
   6. ☐ Others, not part of family livingafu___6 0 = not checked
   7. ☐ Guardian livingafu___7 1 = checked

88. ☐ Declined to answer/Refused livingafu___88
99. ☐ Unknown livingafu__99
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

*BMS Pediatric Proxy 0-7 Interview Form II*

NewMSID____________

6. What is your child’s current school status? \textit{aschoolfuprx}
   1. [ ] In School \textit{(Interviewer Instructions: Continue with \#7 below if this is a 6, 12, or 24 month follow-up. Skip to \#9 on the next page if this is a 5, 10, or 15 year follow-up.)} 
   2. [ ] Not in School \textit{(Interviewer Instructions: Skip to \#9 on the next page)} 
   99. [XX] Unknown

\textit{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? \textit{(Or, as compared with before his/her burn injury, if this is a 6 month follow-up). aprogfuprx}
   \textit{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

\textit{Interviewer instructions: Skip \#8 and move on to \#9 if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.}

8. What was your child’s first date to return to school since the injury? \textit{(Please take your best guess if you don’t know the exact date):} ____/_____/_______ \textit{retrndat}
   \textit{Found in patient status form}

\textit{Interviewer Instructions: Skip to \#10, below, if the child is going to school.}

9. If your child isn’t going to school, why not? \textit{whynotfuprx}
   0. [XX] Not school age
   1. [ ] Burn related
   2. [ ] Other medical problems
   4. [ ] Emotional/social
   5. [ ] Legal/jail
   6. [ ] Substance abuse
   7. [ ] Personal choice
   8. [ ] Other
   77. [XX] Not applicable \textit{(going to school)}

10. How many years of education has your child completed? \textit{(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?”).}

\textit{Interviewer Instructions: Ask the question as open-ended, then mark the appropriate response below. educfupprx}
   0. [ ] Preschool completed 88. [XX] Declined to answer/Refused 
   99. [XX] Unknown
1. ☐ 1 year or less
2. ☐ 2 years
3. ☐ 3 years
77. ☐ Not applicable (child is too young for school)

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

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

14. Does your child currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? cogimpfupprx
   1. ☐ Yes
   2. ☐ No

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

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

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

   1. ☐ Less than $25,000
   2. ☐ $25,000-$49,999
   3. ☐ $50,000-$99,999
   4. ☐ $100,000-$149,999
   5. ☐ $150,000-$199,999
   88. ☐ Declined to answer/Refused
   99. ☐ Unknown
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric Proxy 0-7 Interview Form II
NewMSID___________

6. □ $200,000 or more
7. □ Living outside the United States
77. □ Not applicable (e.g., living in an institution)

16. How many people are in your household? _numhsfupprx_
   (Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

17. Who is the primary sponsor of your child’s care currently? That is, who is paying for the majority of your child’s burn care costs? (Choose only one) _pay_fupprx_
   Notes: In 2018, the categories HMO/PPO/Pre-paid/Managed Care and Private insurance (previously categories 3 and 5) were collapsed into one broader category
   --In 2018, the categories indigent and self-pay (previously categories 7 and 8) were collapsed into one broader category
   --In 2018 clarification was added to #11 that it is the category to select when care was paid for by Shriners. --When changes were made in 2016, existing data was pulled and archived so categories that were collapsed could be expanded with historical data, if necessary.
   1. □ Medicare
   2. □ Medicaid (DSHS)
   3. □ Private insurance/HMO/PPO/Pre-paid/Managed Care
   4. □ Worker’s compensation (L&I)
   6. □ Champus/Tri-Care
   7. □ Self-pay or indigent (public support)
   9. □ VA
10. □ Other
11. □ Philanthropy (private support or private foundation or Shriners hospital)
77. □ Not applicable (no burn care costs)

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. bodyimp_1</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. bodyimp_2</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. This child feels unsure of himself/herself among strangers. bodyimp_3</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. bodyimp_4</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

PEDI Mobility
Total Body Image Proxy Score: bodyim_tot_proxy

I will read you a list of activities. Please choose which response best describes your child’s ability in those activities.

   Unable = Can’t do, doesn’t know how, or is too young = 1
   Hard = Does with a lot of help, extra time, or effort = 2
   A little Hard = Does with a little help, extra time or effort = 3
   Easy=Does with no help, extra time or effort, or child’s skills are past this level= 4
(Please do not consider use of walking devices (walker, crutches or canes) unless specified.)
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

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

**NewMSID__________**

<table>
<thead>
<tr>
<th></th>
<th>Unable=1</th>
<th>Hard=2</th>
<th>A little hard=3</th>
<th>Easy=4</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. When lying on belly, turns head to both sides</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedi_2</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sits on floor without support of pillow or couch</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedi_3</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Walks while holding onto furniture or walls</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedi_4</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Walks outdoors on grass, mulch or gravel</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedi_6</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. When running, is able to go around people and objects</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedi_7</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PEDI Total Score:** pedi_tot

**Interviewer instructions:** If the child is younger than 3, ask the question below and then you are finished with the interview. If the child is between the ages of 3 and 7, continue with the rest of the survey on the next page.

**Indicate time survey ended:** __________

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

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

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

**Interviewer instructions:** If the child is between the ages of 3 and 7, continue with the rest of the survey.

**NIH Toolbox Anger (for children ages 3-7)**

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

<table>
<thead>
<tr>
<th></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>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedproxang01</td>
<td>88 / 99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Argues a lot with adults.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedproxang02</td>
<td>88 / 99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Is easily annoyed by others</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedproxang06</td>
<td>88 / 99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Gets back at people</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pedproxang08</td>
<td>88 / 99</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**NIH Toolbox Anger Proxy 3-7 T-Score:** tbangtscore_proxy
**NIH Toolbox Sadness (for children ages 3-7)**

<table>
<thead>
<tr>
<th>Please indicate how often or true the behavior is of your child.</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. pedproxdep03</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Cries a lot. pedproxdep05</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Seem lonely. pedproxdep06</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Withdraws from peer activities. pedproxdep13</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

**NIH Toolbox General Life Satisfaction (for children ages 3-7)**

<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>
<tbody>
<tr>
<td>1. My child's life is going well. papxy066</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My child's life is just right. papxy067</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My child has a good life. papxy070</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. My child has what he/she wants in life. papxy071</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 with the survey. Thank you very much for your participation in this research study!

Indicate time survey ended: __________
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

BMS Pediatric Proxy 8-17 Interview Form II
NewMSID________________

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 3. ☐ Guardian proxy__3
2. ☐ Father or stepfather proxy__2 4. ☐ Other proxy__4
   proxy__77, not applicable (not proxy)

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

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

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

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

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

Previous variable was called “admin_2”.

4. What is the status of this follow-up assessment? (Choose only one) lostfolo
   1. ☐ Some or all assessment done
   2. ☐ Death due to burn related complications
   3. ☐ Death due to non-burn related complications
   4. ☐ Unable to locate
   5. ☐ Refused this assessment
   6. ☐ Unable to test/med comp/incapable of responding
   7. ☐ Failed to respond
   8. ☐ Did not consent to future assessment/withdrew
   9. ☐ Incarcerated
  10. ☐ Still in hospital (not discharged yet)

Interviewer Instructions: Update date and cause of death on Patient Status Form
14. ☐ Unable to travel for assessment (Option 14 added with new forms in 2015)
15. ☐ Death (unknown causes) (Interviewer Instructions: Update date and cause of death on Patient Status Form) (Option 15 added with new forms in 2018)

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

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

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

**Introduction script:**

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

Thank you for continuing to participate in our study of young people with burn injuries. Like our previous interviews, I’ll be asking questions about your child’s burn injury and other questions about him/her and people around him/her. Your answers will help us understand the experiences of all people with burn injury. You may notice that some questions are similar and feel repetitive. This is not a mistake and is part of the research process. All information will be kept confidential. If you are unsure how to answer a question, please give the answer that fits your child best. You can choose to skip any questions you don’t want to answer or feel uncomfortable answering. Just tell me, “skip.”

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

First I have some questions related to your child’s burn injury…

1. Since your last interview, has your child spoken with other burn survivors to get support for problems related to his/her burn injury? peersupprx  
   - Yes  
   - No

2. Since the last interview, has your child received any of the following services at home or outpatient? (Choose all that apply)  
   If clarification needed:  
   Examples of occupational therapy include helping with adjusting to a school environment after injury. Examples of physical therapy include range of motion and walking exercises.  
   - No services (Interviewer Instructions: skip to #6, surgery item, on the next page) servicesprx  
   - Occupational therapy servicesprx  
   - Physical therapy servicesprx  
   - Speech language pathology servicesprx  
   - Social work servicesprx  
   - Psychological services servicesprx  
   - Vocational services or child life services servicesprx

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

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

3. How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? numtherprx  
   - One  
   - 2-4  
   - 5-10  
   - More than 10  
   - No OT/PT (Interviewer Instructions: skip to #6, surgery item, on the next page)

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

5. Other facility? ther_otrprx  
   - Yes  
   - No  
   - Not applicable (no OT/PT received)
6. Since your last interview [provide date], has your child had any burn related surgeries (such as surgeries for open wounds or scar management)? surgery_fuprx

1. ☐ Yes 88. ☐ Declined to answer/Refused
2. ☐ No (Interviewer Instructions: skip to Child Health Conditions, below)
99. ☐ Don’t know (Interviewer Instructions: skip to Child Health Conditions, below)

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

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

7. Has your child had any burn-related surgeries outside of [name the BMS center]?
surgoutprx

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

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 ☐ No</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 ☐ No</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 ☐ No</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 ☐ No</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 ☐ No</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 ☐ No</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 ☐ No</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 Interview Form II**

**NewMSID____________**

<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>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8. with Teeth and gums? chcprox8, chcprox8a</td>
<td>☐ Yes  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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, chcprox17a</td>
<td>☐ Yes  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. with Pain? chcprox18, chcprox18a</td>
<td>☐ Yes  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Does your child have any other health problems? chcprox19</td>
<td>☐ Yes  ☐ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, specify problem: <em>chcprox19ot (text field)</em></td>
<td></td>
<td>88.</td>
<td>Declined to answer/Refused</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>89.</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain Medication**

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

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

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

4. In the **past 12 months**, did your child take medication for being sad, empty, or depressed? smedproxfup
   1. ☐ Yes
   2. ☐ No
5. Since your last interview, has your child received psychological therapy or counseling due to his/her burn injury? *psychtherprx*
   1. ☐ Yes
   2. ☐ No

*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. <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>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 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 Anger Proxy: angtscore_proxy*

*PROMIS-Depressive Symptoms*

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 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>
</tbody>
</table>
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

### PROMIS Depressive Symptoms T-Score Variable: deptscore_proxy

<table>
<thead>
<tr>
<th>3. My child felt like he/she couldn’t do anything right</th>
<th>88 / 99</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child felt lonely</td>
<td>88 / 99</td>
</tr>
<tr>
<td>My child felt sad</td>
<td>88 / 99</td>
</tr>
<tr>
<td>My child thought that his/her life was bad</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

**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 had pain</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My child felt angry when he/she had pain</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My child had trouble doing schoolwork when he/she had pain</td>
<td>88 / 99</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</td>
<td>88 / 99</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</td>
<td>88 / 99</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</td>
<td>88 / 99</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</td>
<td>88 / 99</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</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

**PROMIS-Peer Relationships**

<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 felt accepted by other kids his/her age</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My child was able to count on his/her friends</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. My child was good at making friends</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. My child and his/her friends helped each other out</td>
<td>88 / 99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Other kids wanted to be my child’s friend</td>
<td>88 / 99</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 Interview Form II**

NewMSID____________

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

**PROMIS-Physical function mobility**

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0=with no trouble</th>
<th>1=with a little trouble</th>
<th>2= With some trouble</th>
<th>3= With a lot of trouble</th>
<th>4=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>
<tr>
<td>2. My child could get up from the floor pf3mobil9</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. My child could keep up when he/she played with other kids pf4mobil4</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. My child could move his/her legs pf3mobil8</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. My child could stand up without help pf3mobil3</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. My child could stand up on his/her tiptoes pf2mobil7</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>7. My child could walk up stairs without holding on to anything pf2mobil4</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>8. My child has been physically able to do the activities he/she enjoys most pf1mobil1</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

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

**PROMIS-Physical function Upper Extremity**

<table>
<thead>
<tr>
<th>In the past 7 days…</th>
<th>0=with no trouble</th>
<th>1=with a little trouble</th>
<th>2= With some trouble</th>
<th>3= With a lot of trouble</th>
<th>4=Not able to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child could button his/her shirt or pants pf2uprext3</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. My child could open a jar by himself/herself pf4uprext1</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. My child could open the rings in school binders pf3uprext11</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. My child could pour a drink from a</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 Interview Form II**

**NewMSID____________**

<table>
<thead>
<tr>
<th>full pitcher pf4uprext10</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>
<th>88 / 99</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. My child could pull a shirt on over his/her head without help pf3uprext4</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>6. My child could pull open heavy doors pf3uprext9</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>7. My child could put on his/her shoes without help pf2uprext2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>8. My child could use a key to unlock a door pf3uprext7</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

**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>
<th>88 / 99</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child's life is going well. papxy066</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. My child's life is just right. papxy067</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. My child has a good life. papxy070</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. My child has what he/she wants in life. papxy071</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>

**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>
<th>88 / 99</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child had trouble sleeping when he/she was itching bmsitchp_1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>2. My child felt angry when he/she was itching bmsitchp_2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>3. My child had trouble doing schoolwork when he/she was itching bmsitchp_3</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>4. It was hard for my child to pay attention when he/she was itching bmsitchp_4</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
<tr>
<td>5. It was hard for my child to have fun when he/she was itching bmsitchp_5</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>88 / 99</td>
</tr>
</tbody>
</table>
**DEMOGRAPHICS**

Next I have some general questions about your child.

*Interviewer instructions: Record participant’s weight and height in pounds and feet/inches and enter it into the database in kg and cm*

1. What is your child’s current weight? (lbs) \_wtfuprx\_ (code 9999 for unknown)

2. What is your child’s current height? (feet/inches) \_htfuprx\_ (code 9999 for unknown)

3. Where is your child currently living? (Choose only one) resden\_c\_fuprx
   - Private residence
   - Nursing home
   - Correctional institution
   - Hotel/motel
   - Homeless
   - Hospital

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

4. What is your child’s current zip code? \_zipfuprx\_ (Code 99999 for unknown, code 00000 for Mexico, code 77777 for homeless)

5. Who is your child currently living with? (Choose all that apply)
   *Interviewer instructions: Probe if needed to make sure that all people child is living with are accounted for in the answer.*
   - Parent or step-parent \_livingafu\_4
   - Other relative (siblings, grandparents) \_livingafu\_5
   - Others, not part of family \_livingafu\_6
   - Guardian \_livingafu\_7

   88. Declined to answer/Refused \_livingafu\_88
   99. Unknown \_livingafu\_99

6. What is your child’s current school status? aschool\_fuprx
   - In School
   - Not in School

   *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.*
   - Same program full time
   - Same program part time
   - New program full time
   - New program part time
   - Did not resume school
   - Returned to individual program, home school

   88. Declined to answer/Refused
   99. Unknown
7. □ Not in school

*Interviewer instructions: Skip #8 and move on to #10 on the next page if there is already a return to work/school date from a previous follow-up. Return to work/school is documented on the Patient Status Form, which should contain this information if it has been previously collected. If return to work/school date is newly recorded, enter on Patient Status Form.*

8. What was your child’s first date to return to school since the injury? (Please take your best guess if you don’t know the exact date): ____/_____/_______ retndat

*Found in patient status form*

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

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

10. How many years of education has your child completed? (*Interviewer Prompt: If necessary, use this prompt to obtain highest level of education completed, “If your child has not graduated from high school, please indicate the number of years spent in school.”) If participant tries to count years rather than degree attained, use the prompt, “In other words, what is the highest level of education your child has completed?”) educfupprx

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

   1. □ 1 year or less
   2. □ 2 years
   3. □ 3 years
   4. □ 4 years
   5. □ 5 years
   6. □ 6 years
   7. □ 7 years
   8. □ 8 years
   9. □ 9 years
   10. □ 10 years
   11. □ 11 or 12 years; no diploma
   12. □ High school diploma
   66. □ Other
   88. □ Declined to answer/Refused
   99. □ Unknown

11. 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, below, if the child is not receiving disability income*)
   2. □ Social Security Disability
   3. □ Private long term insurance disability income
   88. □ Declined to answer/Refused
   99. □ Unknown
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**BMS Pediatric Proxy 8-17 Interview Form II**

**NewMSID____________**

4. □ Supplemental security income (SSI)
5. □ Worker’s compensation
6. □ Other ____

*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 child currently have any permanent cognitive impairments (such as difficulty learning, remembering, or concentrating)? **cogimpfupprx**
   1. □ Yes 2. □ No
   88. □ Declined to answer/Refused
   99. □ Unknown

15. Approximately what was your household’s total income for the last full year (total income of all members of the household)?
   *If clarification is needed about the reason this question is asked, say, “Income is very important in understanding why health outcomes and access to health care are different for different groups of people. Income categories are also used to help develop health and community programs that will best meet the needs of people from different backgrounds.”* **hinccatfupprx**
   *If clarification about currency is needed, say, “these categories are in U.S. dollar amounts.”*
   1. □ Less than $25,000
   2. □ $25,000-$49,999
   3. □ $50,000-$99,999
   4. □ $100,000-$149,999
   5. □ $150,000-$199,999
   6. □ $200,000 or more
   7. □ Living outside the United States
   77. □ Not applicable (e.g., living in an institution)
   88. □ Declined to answer/Refused
   99. □ Unknown

16. How many people are in your household? **numhsfupprx**
   (Code 77 if not applicable; Code 88 if declined to answer/refused; Code 99 if missing/unknown)

17. Who is the primary sponsor of your child’s care currently? That is, who is paying for the majority of your child’s burn care costs? (Choose only one) **pay_fupprx**
   1. □ Medicare
   2. □ Medicaid (DSHS)
   3. □ Private insurance/HMO/PPO/Pre-paid/Managed
   4. □ Worker’s compensation (L&I)
   6. □ Champus/Tri-Care
   88. □ Declined to answer/Refused
   99. □ Unknown
Variable names in red. Numbers for response categories correspond to codes unless otherwise noted.

**Interviewer Instructions:** If the child is younger than 14, ask the question below and then you are finished with the interview. If the child is 14 or older, continue with the CIQ, on the last page.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Self-pay or indigent (public support)</td>
</tr>
<tr>
<td>9</td>
<td>VA</td>
</tr>
<tr>
<td>10</td>
<td>Other</td>
</tr>
<tr>
<td>11</td>
<td>Philanthropy (private support or private foundation or Shriners hospital)</td>
</tr>
<tr>
<td>77</td>
<td>Not applicable (no burn care costs)</td>
</tr>
</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:** ____________

**Interviewer instructions:** If the child is 14 or older, administer the CIQ, below.

**CIQ:**

**Currently:**

1. Does your child take personal responsibility for grooming when asked? *cip2prx*
   1. □ Often 88. □ Declined to answer/Refused
   2. □ Sometimes 99. □ Unknown
   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 88. □ Declined to answer/Refused
   2. □ 1-4 times 99. □ Unknown
   3. □ 5 or more times

3. Leisure activities such as movies, sports, and restaurants. *ci4prx*
   1. □ Never 88. □ Declined to answer/Refused
   2. □ 1-4 times 99. □ Unknown
   3. □ 5 or more times

4. Visiting friends or relatives *ci5prx*
   1. □ Never 88. □ Declined to answer/Refused
   2. □ 1-4 times 99. □ Unknown
   3. □ 5 or more times
5: When your child participates in leisure activities does he/she usually do this alone or with others?  

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

6: Do your child have a best friend with whom he/she can confide?  

- 1. Yes
- 2. No

CIQ Social Integration Score Proxy: ciqsicprx

Is there anything else you would like to tell us?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

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

Indicate time survey ended: ______________