

## BMS Pediatric Proxy 8-17 Interview Form II: Research Staff Instructions

**Instructions:** This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead. Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. 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.

Missing codes appear throughout this interview in small boxes. 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) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

<b>Form II Administration:</b>	
<b>Who is responding to this questionnaire?</b> <b>(Select all that apply)</b> <input type="checkbox"/> 1. Mother or stepmother <input type="checkbox"/> 2. Father or stepfather <input type="checkbox"/> 3. Guardian <input type="checkbox"/> 4. Other	<b>Follow-up period</b> <div style="display: flex; justify-content: space-between;"> <div> <input type="checkbox"/> 1. 6-month follow-up  <input type="checkbox"/> 2. 12 month follow-up  <input type="checkbox"/> 3. 24 month follow-up  <input type="checkbox"/> 4. 5 year follow-up             </div> <div> <input type="checkbox"/> 5. 10 year follow-up  <input type="checkbox"/> 6. 15 year follow-up             </div> </div>
<b>What is the method of administration of this form?</b> <input type="checkbox"/> 1. In person interview <input type="checkbox"/> 3. Telephone interview <input type="checkbox"/> 5. Medical Record Review	<b>What is the language of administration of this form?</b> <input type="checkbox"/> 1. English <input type="checkbox"/> 2. Spanish
<b>What is the status of this follow-up assessment?</b> <input type="checkbox"/> 1. Some or all assessment done <input type="checkbox"/> 2. Death due to burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 3. Death due to non- burn related complications (update date and cause of death on Patient Status Form) <input type="checkbox"/> 4. Unable to locate <input type="checkbox"/> 5. Refused this assessment <input type="checkbox"/> 6. Unable to test/med comp/incapable of responding <input type="checkbox"/> 7. Failed to respond <input type="checkbox"/> 8. Did not consent to future assessment/withdrew <input type="checkbox"/> 11. Incarcerated <input type="checkbox"/> 13. Still in hospital (not discharged yet) <input type="checkbox"/> 14. Unable to travel for assessment <input type="checkbox"/> 15. Death (unknown causes) (update date and cause of death on Patient Status Form)	<b>If follow-up status is "unable to locate," mark the best reason, below:</b> <input type="checkbox"/> 1. Homeless at previous data collection <input type="checkbox"/> 2. International place of residence <input type="checkbox"/> 3. Participant is child who was/is in CPS custody or foster care and no contact information is available <input type="checkbox"/> 4. No known current contact info <input type="checkbox"/> 5. Other reasons <input type="checkbox"/> 6. Unable to contact due to Shriners Hospital regulations

**Burn Model System Follow-up Survey: Introduction**

**Introduction Script** (replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

“Hi my name is \_\_\_\_\_ and I am calling from \_\_\_\_\_ to ask you some questions about how your child has 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. 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 child's burn injury, his/her health, and other questions about your child and people around him/her. 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.” Please let me know at any time if you have any questions.”

Today's Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

“As a reminder, your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.”

“We're going to go ahead and get started.”

**Section I**

I. Since your last research study questionnaire, has your child spoken with other burn survivors to get support for problems related to his/her burn injury?

- ☐ 1. Yes  
☐ 2. No  
☐ 99. I don't know

88/Refused

<p>2. To your knowledge, in the last year has your child had COVID-19?</p> <p><i>Or, since your last research study questionnaire if your child's burn was less than a year ago, has your child had COVID-19?</i></p> <p> <input type="checkbox"/> 1. Yes <span style="margin-left: 100px;">→</span>  <input type="checkbox"/> 2. No  <input type="checkbox"/> 99. I don't know         </p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	<p>(If yes), What month and year did your child have COVID-19? (if your child has had COVID-19 more than once, provide the month and year of his/her <u>first</u> illness)</p> <p>Month: _____ Year: _____</p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused 99/Unknown</div> <p>What level of care did your child receive for COVID-19?</p> <p> <input type="checkbox"/> 1. Did not seek medical care  <input type="checkbox"/> 2. Received medical care but was not hospitalized  <input type="checkbox"/> 3. Was hospitalized         </p> <p>In the hospital... (if applicable)</p> <p> <input type="checkbox"/> 1. He/she was NOT on a ventilator (breathing machine with tube down his/her throat)  <input type="checkbox"/> 2. He/she was on a ventilator  <input type="checkbox"/> 3. I don't know         </p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>
<p>3. Since your last research study questionnaire, has your child received any of the following services at home or outpatient? (Choose all that apply)</p> <p> <input type="checkbox"/> 1. No services  <input type="checkbox"/> 2. Occupational therapy  <input type="checkbox"/> 3. Physical therapy  <input type="checkbox"/> 4. Speech language pathology  <input type="checkbox"/> 5. Social work  <input type="checkbox"/> 6. Psychological services  <input type="checkbox"/> 7. Vocational services or child life services  <input type="checkbox"/> 99. I don't know         </p> <div style="border: 1px solid black; padding: 5px; margin-left: auto; width: 300px;"> <p><i>If clarification is needed, say,</i>  <i>"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."</i></p> </div> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	
<p><b>Interviewer Instructions: If the participant didn't receive any services OR if you didn't receive PT/OT, skip to #8 on page 4</b></p>	
<p>4. If yes to OT and/or PT, How many sessions of occupational and/or physical therapy has your child had in the past 4 weeks? (If you don't know exactly, use your best guess)</p> <p> <input type="checkbox"/> 1. One  <input type="checkbox"/> 2. 2 to 4  <input type="checkbox"/> 3. 5 to 10  <input type="checkbox"/> 4. More than 10  <input type="checkbox"/> 77. Not applicable (no OT/PT received) <span style="margin-left: 20px;">→ skip to #8 on page 4</span>  <input type="checkbox"/> 99. I don't know         </p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	
<p><i>If yes to OT and/or PT, Since your last research study questionnaire, <u>where</u> did your child receive his/her outpatient occupational or physical burn therapy?</i></p>	
<p>5. At the burn center?</p> <p> <input type="checkbox"/> 1. Yes  <input type="checkbox"/> 2. No  <input type="checkbox"/> 77. Not applicable (no OT/PT received)  <input type="checkbox"/> 99. I don't know         </p> <div style="border: 1px solid black; padding: 2px; width: fit-content; margin-left: auto;">88/Refused</div>	

<p>6. At any other facility?</p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>		88/Refused
<p>7. Using telehealth? (for example, meeting with his/her therapist using video conferencing)</p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 77. Not applicable (no OT/PT received)</p> <p><input type="checkbox"/> 99. I don't know</p>		88/Refused
<p>8. Since your last research study questionnaire, has your child had any burn related surgeries (such as surgeries for open wounds or scar management)?</p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	<p>(If your child <u>did</u> have burn related surgeries) Has your child had any burn-related surgeries outside of this clinical center?</p> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p>	<p>88/Refused</p> <p>88/Refused</p>

## Section 2

*“Please answer each question with a “yes” or “no”. If you answer “yes”, then please indicate to what extent this problem affects your child’s daily activities using these responses:”*

*Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

[illegible]

Does your child have problems...	Problem?	1	2	3	4	5	6	7
13. with Repeated infections?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. with Breathing (eg asthma)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with Chronic open skin areas (eg chronic open wounds)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with other Skin problems (eg eczema)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the Heart (such as a birth defect)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Does your child have any other health problems?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, specify problem:						

### Section 3

1. Is your child **currently** taking prescription medication for pain on a regular basis?

- ☐ 1. Yes  
☐ 2. No  
☐ 99. I don't know

88/Refused

2. Is your child **currently** taking prescription medication for itch on a regular basis?

- ☐ 1. Yes  
☐ 2. No  
☐ 99. I don't know

88/Refused

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

- ☐ 1. Yes  
☐ 2. No  
☐ 99. I don't know

88/Refused

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

- ☐ 1. Yes  
☐ 2. No  
☐ 99. I don't know

88/Refused

5. Since your last research study questionnaire, has your child received psychological therapy or counseling due to his/her burn injury?

- ☐ 1. Yes  
☐ 2. No  
☐ 99. I don't know

88/Refused

**Section 4***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***The following questions ask about this child's appearance:**

	<b>Definitely true = 1</b>	<b>Mostly true = 2</b>	<b>Not sure = 3</b>	<b>Mostly false = 4</b>	<b>Definitely false = 5</b>
1. This child feels that the burn is unattractive to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This child thinks that people would not want to touch him/her.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. This child feels unsure of himself/herself among strangers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Changes in this child's appearance have interfered with his/her relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 5***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child felt mad.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child was so angry he/she felt like yelling at somebody.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child was so angry he/she felt like throwing something.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child felt upset.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When my child got mad, he/she stayed mad...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 6***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>Physical Function Mobility</b> <b>In the past 7 days...</b>	<b>With no trouble</b>	<b>With a little trouble</b>	<b>With some trouble</b>	<b>With a lot of trouble</b>	<b>Not able to do</b>
My child could do sports and exercise that other kids his/her age could do.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child could get up from the floor.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child could walk up stairs without holding on to anything.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has been physically able to do the activities he/she enjoys most.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Anxiety</b> <b>In the past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child felt like something awful might happen...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child felt nervous.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child felt worried.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child worried when he/she was at home.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Depressive Symptoms</b> <b>In the past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child felt everything in his/her life went wrong.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child felt lonely.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child felt sad.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was hard for my child to have fun.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Fatigue</b> <b>In past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
Being tired made it hard for my child to keep up with schoolwork.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child got tired easily.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child was too tired to do sports or exercise ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child was too tired to enjoy the things he/she likes to do.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Peer Relationships</b> <b>In the past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child felt accepted by other kids his/her age...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child was able to count on his/her friends.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and his/her friends helped each other out.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other kids wanted to be my child's friend.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Pain Interference</b> <b>In the past 7 days...</b>	<b>Never</b>	<b>Almost never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
My child had trouble sleeping when he/she had pain.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was hard for my child to pay attention when he/she had pain.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was hard for my child to run when he/she had pain .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was hard for my child to walk one block when he/she had pain.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Pain Intensity</b> <b>In the past 7 days...</b>												
How bad was your child's pain on average?...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	0	1	2	3	4	5	6	7	8	9	10	
	<b>No pain</b>										<b>Worst pain you can think of</b>	
88/Refused												
99/Unknown												

<b>Section 7</b>					
<i>Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.</i>					
<b>Please respond to each question or statement by marking one box per row.</b>					
<b>In the past 7 days...</b>	<b>With no trouble</b>	<b>With a little trouble</b>	<b>With some trouble</b>	<b>With a lot of trouble</b>	<b>Not able to do</b>
My child could button his/her shirt or pants	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could open a jar by himself/herself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could open the rings in school binders.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could pour a drink from a full pitcher.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could pull a shirt on over his/her head without help.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could pull open heavy doors.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could put on his/her shoes without help.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child could use a key to unlock a door	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5



**Section 8***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.*

Indicate how much you agree or disagree:

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1. My child's life is going well.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My child's life is just right.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My child has a good life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. My child has what he/she wants in life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 9***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days ...</b>		<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child had trouble sleeping when he/she was itching		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child felt angry when he/she was itching		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was hard for my child to pay attention when he/she was itching		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was hard for my child to have fun when he/she was itching		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>N/A</b> (He/she doesn't do schoolwork)	<b>Never</b>	<b>Almost Never</b>	<b>Some-times</b>	<b>Often</b>	<b>Almost Always</b>
My child had trouble doing schoolwork when he/she was itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 10***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>No days</b>	<b>1 day</b>	<b>2-3 days</b>	<b>4-5 days</b>	<b>6-7 days</b>
How many days did your child exercise or play so hard that his/her body got tired? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did your child exercise really hard for 10 minutes or more? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days did your child exercise so much that he/she breathed hard?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How many days was your child so physically active that he/she sweated?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 11***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 7 days...</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Almost Always</b>	<b>Always</b>
My child had difficulty falling asleep.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child slept through the night.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child had a problem with his/her sleep...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child had trouble sleeping.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Section 12***Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.***Please respond to each question or statement by marking one box per row.**

<b>In the past 4 weeks...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
My child felt he/she had a strong relationship with our family.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt he/she was really important to our family.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My child felt he/she got all the help he/she needed from our family.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Our family and my child had fun together...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Section 13	
1. What is your child's current weight? (lbs) _____ <input type="checkbox"/> I don't know	88/Refused
2. What is your child's current height? (feet/inches) _____ <input type="checkbox"/> I don't know	88/Refused
3. Where is your child currently living? (Choose only one) <div style="margin-left: 20px;"> <input type="checkbox"/> 1. Private residence  <input type="checkbox"/> 2. Nursing home  <input type="checkbox"/> 4. Correctional institution  <input type="checkbox"/> 5. Hotel/motel  <input type="checkbox"/> 6. Homeless  <input type="checkbox"/> 7. Hospital           </div>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
4. What is your child's current zip code? ____-____-____ <input type="checkbox"/> Not applicable (not living in U.S.) <span style="margin-left: 50px;"><input type="checkbox"/> Not applicable (homeless)</span> <small>(code 99999 for unknown)</small>	
5. Who is your child currently living with? (Choose all that apply) <div style="margin-left: 20px;"> <input type="checkbox"/> 4. Parent or step-parent  <input type="checkbox"/> 5. Other relative (siblings, grandparents)  <input type="checkbox"/> 6. Others, not part of family  <input type="checkbox"/> 7. Guardian           </div>	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
6. What is your child's current school status? <input type="checkbox"/> 1. In school <input type="checkbox"/> 2. Not in school	<div style="border-left: 1px solid black; padding-left: 10px;"> <i>If your child isn't going to school, why not?</i>  <input type="checkbox"/> Burn related  <input type="checkbox"/> Other medical problems  <input type="checkbox"/> Emotional/social reasons  <input type="checkbox"/> Legal reasons/jail  <input type="checkbox"/> Substance abuse  <input type="checkbox"/> Personal choice  <input type="checkbox"/> Other  <input type="checkbox"/> Not applicable (going to school)  <input type="checkbox"/> I don't know           </div>
<div style="display: flex; justify-content: space-between;"> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> </div>	
7. <i>Interviewer instructions: If the child hadn't already returned to school before their last research study questionnaire, but the child is in school now, say:</i> What was your child's first date to return to school since his/her injury? (Please take your best guess if you don't know the exact date): ____/____/____	

<p><b>8. How many years of education has your child completed?</b></p> <div style="display: flex; justify-content: space-between;"> <div style="width: 80%;"> <p><input type="checkbox"/> 1. 1 year or less</p> <p><input type="checkbox"/> 2. 2 years</p> <p><input type="checkbox"/> 3. 3 years</p> <p><input type="checkbox"/> 4. 4 years</p> <p><input type="checkbox"/> 5. 5 years</p> <p><input type="checkbox"/> 6. 6 years</p> <p><input type="checkbox"/> 7. 7 years</p> <p><input type="checkbox"/> 8. 8 years</p> <p><input type="checkbox"/> 9. 9 years</p> <p><input type="checkbox"/> 10. 10 years</p> <p><input type="checkbox"/> 11. 11 or 12 years; no diploma</p> <p><input type="checkbox"/> 12. High school diploma or equivalent (ie, GED)</p> <p><input type="checkbox"/> 66. Other</p> </div> <div style="width: 15%; text-align: center;"> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div> </div> </div>	
<p><b>9. Is your child currently receiving <u>disability</u> income such as Social Security Disability?</b> (Choose all that apply)</p> <div style="display: flex; align-items: center;"> <div style="width: 40%;"> <p><input type="checkbox"/> 1. My child is not receiving disability income</p> <p><input type="checkbox"/> 2. Social Security Disability</p> <p><input type="checkbox"/> 4. Supplemental security income (SSI)</p> <p><input type="checkbox"/> 6. Other (please specify) _____</p> <p><input type="checkbox"/> 99. I don't know</p> </div> <div style="width: 10%; text-align: center;"> <div style="border: 1px solid black; padding: 2px; margin-top: 20px;">88/Refused</div> </div> </div>	<p><i>If yes, is your child receiving disability income due to his/her burn injury?</i></p> <p><input type="checkbox"/> 1. Yes, my child is receiving disability income due to his/her burn injury</p> <p><input type="checkbox"/> 2. No, my child is not receiving disability income due to his/her burn injury</p> <p><input type="checkbox"/> 77. Not applicable (not receiving disability income)</p> <p><input type="checkbox"/> 99. I don't know</p> <div style="text-align: center; margin-top: 10px;"> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> </div>
<p><b>10. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)?</b></p> <div style="display: flex; justify-content: space-between;"> <div style="width: 80%;"> <p><input type="checkbox"/> 1. Yes</p> <p><input type="checkbox"/> 2. No</p> <p><input type="checkbox"/> 99. I don't know</p> </div> <div style="width: 15%; text-align: center;"> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> </div> </div>	

“The following question asks about your income. We appreciate this information because income is often related to health. For instance, we’d like to know if families with lower reported income have more trouble accessing health care, such as dental care or physical therapy. Having this information helps us advocate for better programs that serve people with burn injuries.”

11. Approximately what was your family’s total income for the last full year (total income of all family members living with you in your household)? (in U.S. dollars)

99/Unknown

- ☐ 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. Prefer not to answer

12. How many people are in your household? \_\_\_\_\_

88/Refused

99/Unknown

13. 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)

88/Refused

- ☐ 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)
- ☐ 99. I don’t know

**Interviewer Instructions:** *If the child is **under 14 years old**, you are **finished** with the interview.*

*If the child is **between 14 and 17 years old**, please complete **Section 14** below.*

Length of interview: \_\_\_\_\_

**If the child is under 14 years old**, say, “is there anything else you would like to tell us?”

“Thank you very much for sharing your experiences with us.”

<b>Section 14</b>	
<i>Interviewer Instructions: If the child is <b>between 14 and 17 years old</b>, please complete Section 14, below.</i>	
<b>Currently:</b>	
1. Does your child take personal responsibility for grooming when asked? <input type="checkbox"/> 1. Often <input type="checkbox"/> 2. Sometimes <input type="checkbox"/> 3. Never	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
<b>Approximately how many times a month does your child usually participate in the following activities outside of your home?</b>	
2. Shopping <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
3. Leisure activities such as movies, sports, and restaurants. <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
4. Visiting friends or relatives <input type="checkbox"/> 1. Never <input type="checkbox"/> 2. One to four times <input type="checkbox"/> 3. 5 or more times	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
5. When your child participate in leisure activities does he/she usually do this alone or with others? <input type="checkbox"/> 1. Mostly alone <input type="checkbox"/> 2. Mostly with friends who have burn injuries <input type="checkbox"/> 3. Mostly with family members <input type="checkbox"/> 4. Mostly with friends who do not have burn injuries <input type="checkbox"/> 5. With a combination of family and friends <input type="checkbox"/> 77. Not applicable (no leisure activities)	<div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
6. Does your child have a best friend with whom he/she can confide? <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know	<div style="border: 1px solid black; padding: 2px;">88/Refused</div>
Length of survey: _____  "Is there anything else you would like to tell us? _____ _____ _____ _____ Thank you very much for sharing your experiences with us."	