

## **BMS Pediatric Proxy 0-7 Mail Form II: Research Staff Instructions**

**Instructions:** The first page should be filled out by research staff and then separated from the mail form before sending or giving to the participant. Fill in contact information at the end of the Introduction for participant in case of questions before sending out mail form or before handing to participant.

After receiving the completed form in the mail or from a participant, go through the survey over 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" (Don't know/Unknown) next to the item.

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 filling out this questionnaire? (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> <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
<b>What is the method of administration of this form?</b> <input type="checkbox"/> 2. Mail <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

Thank you for continuing to participate in this study! We want to learn about how children do after a burn injury. Some questions are about your child's burn injury and other questions ask about him/her and people around him/her. You may notice that some questions might sound similar. This is not a mistake and is part of the research process. All your information will be kept private. 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. Some questions have instructions to help you answer them better. These instructions appear in italics.

**Please answer all questions as best you can. If you have any questions please contact us at: \_\_\_\_\_.**

**Your last research study questionnaire was completed on \_\_\_\_/\_\_\_\_/\_\_\_\_.**

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

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

- |  |                                      |
|--|--------------------------------------|
| <input type="checkbox"/> 1. Mother or stepmother | <input type="checkbox"/> 3. Guardian |
| <input type="checkbox"/> 2. Father or stepfather | <input type="checkbox"/> 4. Other    |

### Section I

1. 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  
☐ 77. Not applicable  
☐ 99. I don't know

2. To your knowledge, in the last year has your child had COVID-19?

*Or, since your last research study questionnaire if your child's burn was less than a year ago, has your child had COVID-19?*

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

*(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 first illness)*

Month: \_\_\_\_\_

Year: \_\_\_\_\_

What level of care did your child receive for COVID-19?

- ☐ 1. Did not seek medical care  
☐ 2. Received medical care but was not hospitalized  
☐ 3. Was hospitalized

*In the hospital... (if applicable)*

- ☐ 1. He/she was NOT on a ventilator (breathing machine with tube down his/her throat)  
☐ 2. He/she was on a ventilator  
☐ 3. I don't know

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

- ☐ 1. No services
- ☐ 2. Occupational therapy
- ☐ 3. Physical therapy
- ☐ 4. Speech language pathology
- ☐ 5. Social work
- ☐ 6. Psychological services
- ☐ 7. Vocational services or child life services
- ☐ 99. I don't know

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.

**If your child didn't receive any services OR if he/she didn't receive PT/OT, skip to #8 on page 4**

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)

- ☐ 1. One
- ☐ 2. 2 to 4
- ☐ 3. 5 to 10
- ☐ 4. More than 10
- ☐ 77. Not applicable (no OT/PT received) → skip to #8 on page 4
- ☐ 99. I don't know

If yes to OT and/or PT, Since your last research study questionnaire, where did your child receive his/her outpatient occupational or physical burn therapy?

5. At the burn center?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 77. Not applicable (no OT/PT received)
- ☐ 99. I don't know

6. At any other facility?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 77. Not applicable (no OT/PT received)
- ☐ 99. I don't know

7. Using telehealth? (for example, meeting with his/her therapist using video conferencing)

- ☐ 1. Yes
- ☐ 2. No
- ☐ 77. Not applicable (no OT/PT received)
- ☐ 99. I don't know

<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>
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## Section 2

**Instructions:** 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:

1 Not at all	2 To a very small extent	3 To a small extent	4 To a moderate extent	5 To a fairly great extent	6 To a great extent	7 To a very great extent					
Does your child have problems...				Problem?	1	2	3	4	5	6	7
1. Seeing?				<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"/>
2. Hearing?				<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"/>
3. Learning and understanding?				<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"/>
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)?				<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"/>
5. Controlling emotions or behavior?				<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"/>
6. with Seizures or epilepsy?				<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"/>
7. involving the Mouth (eg, chewing, swallowing, and drooling)?				<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"/>
8. with Teeth and gums?				<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"/>
9. with Digestion (eg reflux, vomiting, or constipation)?				<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"/>
10. with Type 1 or Type 2 diabetes?				<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"/>
11. with Growth?				<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"/>
12. Sleeping?				<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"/>
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**

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

	<b>Not at all = 0</b>	<b>A little bit = 1</b>	<b>Some- what = 2</b>	<b>Quite a bit = 3</b>	<b>Very much = 4</b>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 4**

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

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

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

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

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

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

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

**Section 5**

1. What is your child's current weight? (lbs) \_\_\_\_\_ ☐ I don't know

2. What is your child's current height? (feet/inches) \_\_\_\_\_ ☐ I don't know

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

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

4. What is your child's current zip code? \_\_\_\_-\_\_\_\_-\_\_\_\_

- ☐ Not applicable (not living in U.S.) ☐ Not applicable (homeless)

5. Who is your child 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

6. What is your child's current school status?

- ☐ 1. In school
- ☐ 2. Not in school

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


- ☐ Not school age
- ☐ Burn related
- ☐ Other medical problems
- ☐ Emotional/social reasons
- ☐ Personal choice
- ☐ Other
- ☐ Not applicable (going to school)
- ☐ I don't know

7. *If your child hadn't already returned to school before your last research study questionnaire, but your child is in school now,*

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): \_\_\_\_/\_\_\_\_/\_\_\_\_

8. How many years of education has your child completed?

- ☐ 0. Preschool completed
- ☐ 1. 1 year or less
- ☐ 2. 2 years
- ☐ 3. 3 years
- ☐ 4. 4 years
- ☐ 77. Not applicable (child is too young for school)

<p>9. Is your child currently receiving <u>disability</u> income such as Social Security Disability? (Choose all that apply)</p> <div style="display: flex; align-items: flex-start;"> <div style="margin-right: 20px;">  <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. My child is not receiving disability income</li> <li><input type="checkbox"/> 2. Social Security Disability</li> <li><input type="checkbox"/> 4. Supplemental security income (SSI)</li> <li><input type="checkbox"/> 6. Other (please specify) _____</li> <li><input type="checkbox"/> 99. I don't know</li> </ul> </div> <div style="border-left: 1px solid black; padding-left: 10px;"> <p>→</p> </div> </div>	<p><i>If yes, is your child receiving disability income due to his/her burn injury?</i></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. Yes, my child is receiving disability income due to his/her burn injury</li> <li><input type="checkbox"/> 2. No, my child is not receiving disability income due to his/her burn injury</li> <li><input type="checkbox"/> 77. Not applicable (not receiving disability income)</li> <li><input type="checkbox"/> 99. I don't know</li> </ul>
<p>10. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)?</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. Yes</li> <li><input type="checkbox"/> 2. No</li> <li><input type="checkbox"/> 99. I don't know</li> </ul>	
<p>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.</p>	
<p>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)</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 1. Less than \$25,000</li> <li><input type="checkbox"/> 2. \$25,000-\$49,999</li> <li><input type="checkbox"/> 3. \$50,000-\$99,999</li> <li><input type="checkbox"/> 4. \$100,000-\$149,999</li> <li><input type="checkbox"/> 5. \$150,000-\$199,999</li> <li><input type="checkbox"/> 6. \$200,000 or more</li> <li><input type="checkbox"/> 7. Living outside the United States</li> <li><input type="checkbox"/> 77. Not applicable (e.g., living in an institution)</li> <li><input type="checkbox"/> 88. Prefer not to answer</li> </ul>	
<p>12. How many people are in your household? _____</p>	

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)

- ☐ 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

## Section 6

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 7**

Below is a list of activities. Please choose which response best describes your child's ability in those activities.

Unable = Can't do, doesn't know how, or is too young = 1

Hard = Does with a lot of help, extra time, or effort = 2

A little Hard = Does with a little help, extra time or effort = 3

Easy=Does with no help, extra time or effort, or child's skills are past this level= 4

(Please do not consider use of walking devices (walker, crutches or canes) unless specified.)

Please choose which answer best describes your child's abilities in the following activities.	Unable	Hard	A little hard	Easy
1. When lying on belly, turns head to both sides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Sits on floor without support of pillow or couch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Walks while holding onto furniture or walls	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Walks outdoors on grass, mulch or gravel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. When running, is able to go around people and objects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

***Instructions: If your child is younger than 3 years old please skip to the next page and answer the last questions in Section 10.***

**Section 8 (for children ages 3-7 only)**

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

	0=Never or not true	1=Sometimes or somewhat true	2=Often or very true
1. Has temper tantrums or hot temper.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Argues a lot with adults.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is easily annoyed by others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Gets back at people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

**Section 8 continued (for children ages 3-7 only)**

	<b>0=Never or not true</b>	<b>1=Sometimes or somewhat true</b>	<b>2=Often or very true</b>
1. Is unhappy, sad or depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Cries a lot.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Seems lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Withdraws from peer activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 9 (for children ages 3-7 only)**

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

**Section 10**

How long did this survey take you to complete? \_\_\_\_\_

Is there anything else you would like to tell us? \_\_\_\_\_

\_\_\_\_\_  
 \_\_\_\_\_

Thank you very much for sharing your experiences with us!