BMS Pediatric Proxy 8-17 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.

Form II Administration:

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

- ☐ 1. Mother or stepmother
- ☐ 2. Father or stepfather
- ☐ 3. Guardian
- ☐ 4. Other

Follow-up period

- ☐ 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

What is the method of administration of this form?

- ☐ 2. Mail
- ☐ 5. Medical Record Review

What is the language of administration of this form?

- ☐ 1. English
- ☐ 2. Spanish

What is the status of this follow-up assessment?

- ☐ 1. Some or all assessment done
- ☐ 2. Death due to burn related complications (update date and cause of death on Patient Status Form)
- ☐ 3. Death due to non- burn related complications (update date and cause of death on Patient Status Form)
- ☐ 4. Unable to locate
- ☐ 5. Refused this assessment
- ☐ 6. Unable to test/med comp/incapable of responding
- ☐ 7. Failed to respond
- ☐ 8. Did not consent to future assessment/withdrew
- ☐ 11. Incarcerated
- ☐ 13. Still in hospital (not discharged yet)
- ☐ 14. Unable to travel for assessment
- ☐ 15. Death (unknown causes) (update date and cause of death on Patient Status Form)

If follow-up status is "unable to locate," mark the best reason, below:

- ☐ 1. Homeless at previous data collection
- ☐ 2. International place of residence
- ☐ 3. Participant is child who was/is in CPS custody or foster care and no contact information is available
- ☐ 4. No known current contact info
- ☐ 5. Other reasons
- ☐ 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 young people 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)

- ☐ 1. Mother or stepmother
- ☐ 2. Father or stepfather
- ☐ 3. Guardian
- ☐ 4. Other

Section 1

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
   - ☐ 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 <u>first</u> 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, <u>where</u> 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

8. Since your last research study questionnaire, has your child had any burn related surgeries (such as surgeries for open wounds or scar management)? ☐ 1. Yes ➡ ☐ 2. No ☐ 99. I don't know	*(If your child <u>did</u> have burn related surgeries)* Has your child had any burn-related surgeries outside of this clinical center? ☐ 1. Yes ☐ 2. No ☐ 99. I don't know

Section 2

<u>Instructions</u>: 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?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
2. Hearing?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
3. Learning and understanding?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
4. Speaking or communicating in other ways (eg, signs, gestures, picture cards, or sounds that are not words)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
5. Controlling emotions or behavior?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
6. with Seizures or epilepsy?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
7. involving the Mouth (eg, chewing, swallowing, and drooling)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
8. with Teeth and gums?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
9. with Digestion (eg reflux, vomiting, or constipation)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
10. with Type 1 or Type 2 diabetes?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
11. with Growth?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
12. Sleeping?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
13. with Repeated infections?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
14. with Breathing (eg asthma)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
15. with Chronic open skin areas (eg chronic open wounds)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
16. with other Skin problems (eg eczema)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
17. with the Heart (such as a birth defect)?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
18. with Pain?	☐Yes	☐No	☐	☐	☐	☐	☐	☐	☐
19. Does your child have any other health problems?	☐Yes	☐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

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 4

The following questions ask about this child's appearance:

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

Section 5					
Please respond to each question or statement by marking one box per row.					
In the past 7 days…	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
My child felt mad……	☐	☐	☐	☐	☐
My child was so angry he/she felt like yelling at somebody……..	☐	☐	☐	☐	☐
My child was so angry he/she felt like throwing something……..	☐	☐	☐	☐	☐
My child felt upset……	☐	☐	☐	☐	☐
When my child got mad, he/she stayed mad…	☐	☐	☐	☐	☐

Section 6					
Please respond to each question or statement by marking one box per row.					
<u>Physical Function Mobility</u> In the past 7 days…	**With no trouble**	**With a little trouble**	**With some trouble**	**With a lot of trouble**	**Not able to do**
My child could do sports and exercise that other kids his/her age could do……..	☐	☐	☐	☐	☐
My child could get up from the floor……	☐	☐	☐	☐	☐
My child could walk up stairs without holding on to anything……..	☐	☐	☐	☐	☐
My child has been physically able to do the activities he/she enjoys most……	☐	☐	☐	☐	☐
<u>Anxiety</u> In the past 7 days…	**Never**	**Almost never**	**Some-times**	**Often**	**Almost Always**
My child felt like something awful might happen…	☐	☐	☐	☐	☐
My child felt nervous……..	☐	☐	☐	☐	☐
My child felt worried……	☐	☐	☐	☐	☐
My child worried when he/she was at home……	☐	☐	☐	☐	☐

Depressive Symptoms **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost Always**
My child felt everything in his/her life went wrong……	☐	☐	☐	☐	☐
My child felt lonely……	☐	☐	☐	☐	☐
My child felt sad……..	☐	☐	☐	☐	☐
It was hard for my child to have fun……..	☐	☐	☐	☐	☐
Fatigue **In past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost Always**
Being tired made it hard for my child to keep up with schoolwork……	☐	☐	☐	☐	☐
My child got tired easily……	☐	☐	☐	☐	☐
My child was too tired to do sports or exercise …	☐	☐	☐	☐	☐
My child was too tired to enjoy the things he/she likes to do……..	☐	☐	☐	☐	☐
Peer Relationships **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost Always**
My child felt accepted by other kids his/her age…	☐	☐	☐	☐	☐
My child was able to count on his/her friends……	☐	☐	☐	☐	☐
My child and his/her friends helped each other out……	☐	☐	☐	☐	☐
Other kids wanted to be my child's friend…….	☐	☐	☐	☐	☐
Pain Interference **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost Always**
My child had trouble sleeping when he/she had pain……	☐	☐	☐	☐	☐
It was hard for my child to pay attention when he/she had pain……..	☐	☐	☐	☐	☐
It was hard for my child to run when he/she had pain ……..	☐	☐	☐	☐	☐
It was hard for my child to walk one block when he/she had pain……	☐	☐	☐	☐	☐

Pain Intensity In the past 7 days…											
How bad was your child's pain on average?...	☐ 0 **No pain**	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10 **Worst pain you can think of**

Section 7					
Please respond to each question or statement by marking one box per row.					
In the past 7 days…	**With no trouble**	**With a little trouble**	**With some trouble**	**With a lot of trouble**	**Not able to do**
My child could button his/her shirt or pants	☐	☐	☐	☐	☐
My child could open a jar by himself/herself	☐	☐	☐	☐	☐
My child could open the rings in school binders……..	☐	☐	☐	☐	☐
My child could pour a drink from a full pitcher……	☐	☐	☐	☐	☐
My child could pull a shirt on over his/her head without help……	☐	☐	☐	☐	☐
My child could pull open heavy doors……	☐	☐	☐	☐	☐
My child could put on his/her shoes without help……..	☐	☐	☐	☐	☐
My child could use a key to unlock a door	☐	☐	☐	☐	☐

Section 8					
Indicate how much you agree or disagree:					
	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. My child's life is going well.	☐	☐	☐	☐	☐
2. My child's life is just right.	☐	☐	☐	☐	☐
3. My child has a good life.	☐	☐	☐	☐	☐
4. My child has what he/she wants in life.	☐	☐	☐	☐	☐

Section 9

Please respond to each question or statement by marking one box per row.

In the past 7 days …	Never	Almost Never	Some-times	Often	Almost Always
My child had trouble sleeping when he/she was itching	☐	☐	☐	☐	☐
My child felt angry when he/she was itching	☐	☐	☐	☐	☐
It was hard for my child to pay attention when he/she was itching	☐	☐	☐	☐	☐
It was hard for my child to have fun when he/she was itching	☐	☐	☐	☐	☐

	N/A (He/she doesn't do schoolwork)	Never	Almost Never	Some-times	Often	Almost Always
My child had trouble doing schoolwork when he/she was itching	☐	☐	☐	☐	☐	☐

Section 10

Please respond to each question or statement by marking one box per row.

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

Section 11

Please respond to each question or statement by marking one box per row.

In the past 7 days…	Never	Almost Never	Some-times	Almost Always	Always
My child had difficulty falling asleep…….	☐	☐	☐	☐	☐
My child slept through the night…….	☐	☐	☐	☐	☐
My child had a problem with his/her sleep…	☐	☐	☐	☐	☐
My child had trouble sleeping……	☐	☐	☐	☐	☐

Section 12					
Please respond to each question or statement by marking one box per row.					
In the past 4 weeks…	**Never**	**Rarely**	**Some-times**	**Often**	**Always**
My child felt he/she had a strong relationship with our family…….	☐	☐	☐	☐	☐
My child felt he/she was really important to our family…….	☐	☐	☐	☐	☐
My child felt he/she got all the help he/she needed from our family…….	☐	☐	☐	☐	☐
Our family and my child had fun together…	☐	☐	☐	☐	☐

Section 13

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? ☐ Burn related ☐ Other medical problems ☐ Emotional/social reasons ☐ Legal reasons/jail ☐ Substance abuse ☐ 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?
- ☐ 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 or equivalent (ie, GED)
- ☐ 66. Other

9. Is your child currently receiving <u>disability</u> income such as Social Security Disability? (Choose all that apply) ☐ 1. My child is not receiving disability income ☐ 2. Social Security Disability ☐ 4. Supplemental security income (SSI) ☐ 6. Other (please specify) _____ ☐ 99. I don't know	*If yes*, is your child receiving disability income due to his/her burn injury? ☐ 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. I don't know
10. Does your child currently have any physical problems, such as a mobility impairment (difficulty moving his/her arms, legs or body)? ☐ 1. Yes ☐ 2. No ☐ 99. I don't know	
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) ☐ 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? _____	

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 14

Instructions: ***If your child is 13 years old or younger please skip this section and answer the questions in Section 8.***

If your child is between 14 and 17 years old, please answer the questions below.

Currently:

1. Does your child take personal responsibility for grooming when asked?
   - ☐ 1. Often
   - ☐ 2. Sometimes
   - ☐ 3. Never

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

2. Shopping
   - ☐ 1. Never
   - ☐ 2. One to four times
   - ☐ 3. 5 or more times

3. Leisure activities such as movies, sports, and restaurants.
   - ☐ 1. Never
   - ☐ 2. One to four times
   - ☐ 3. 5 or more times

4. Visiting friends or relatives
   - ☐ 1. Never
   - ☐ 2. One to four times
   - ☐ 3. 5 or more times

5. When your child participate 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. Does your child have a best friend with whom he/she can confide?
- ☐ 1. Yes
- ☐ 2. No
- ☐ 99. I don't know

Section 8

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!