BMS Pediatric Self Report 13-17 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:

Follow-up period	**What is the method of administration of this form?**	**What is the language of administration of this form?**
☐ 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	☐ 2. Mail ☐ 5. Medical Record Review	☐ 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 be a part of this study! We want to learn about how young people do after a burn injury. Some questions are about your burn injury and other questions ask about you and people around you. 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 the best you can.

If you have any questions please contact us at: _____.

Your last research study questionnaire was completed on ___/____/_____.

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

Section 1

1. Since your last research study questionnaire, have you spoken with other burn survivors to get support for problems related to your burn injury?

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

2. To your knowledge, in the last year have you had COVID. 19?

Or, since your last research study questionnaire if your burn was less than a year ago, have you had COVID. 19?

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

(*If yes*), What month and year did you have COVID. 19?
(*if you've had COVID. 19 more than once, provide the month and year of your <u>first</u> illness*)

Month:_____
Year: _____

What level of care did you 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. I was NOT on a ventilator (breathing machine with tube down your throat)
- ☐ 2. I was on a ventilator
- ☐ 3. I don't know

3. Since your last research study questionnaire, have you 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 you didn't receive any services OR if you 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 have you 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 you receive your 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 your 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, have you had any burn related surgeries (such as surgeries for open wounds or scar management)? ☐ 1. Yes ➡ ☐ 2. No ☐ 99. I don't know	*(If you <u>did</u> have burn related surgeries)* Have you had any burn. related surgeries outside of this clinical center? ☐ 1. Yes ☐ 2. No ☐ 99. I don't know

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 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*

Do you 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 you have any other health problems?	☐Yes	☐No	If yes, specify problem:						

Section 3

1. Are you **currently** taking prescription medication for pain on a regular basis?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

2. Are you **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 you take medication for being, worried, tense, or anxious?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

4. In the past 12 months, did you take medication for being sad, empty, or depressed?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

5. Since your last research study questionnaire, have you received psychological therapy or counseling due to your burn injury?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

Section 4

The following questions ask about your appearance:

	Definitely true = 1	**Mostly true = 2**	**Not sure = 3**	**Mostly false = 4**	**Definitely false = 5**
1. I feel that the burn is unattractive to others.	☐	☐	☐	☐	☐
2. I think people would not want to touch me.	☐	☐	☐	☐	☐
3. I feel unsure of myself among strangers.	☐	☐	☐	☐	☐
4. Changes in my appearance have interfered with my relationships.	☐	☐	☐	☐	☐

Section 5				
This is a list of problems that kids sometimes have after experiencing an upsetting event. Read each one carefully and then choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.				
	Not at all or only at one time	**Once a week or less/ once in a while**	**2 to 4 times a week/ half the time**	**5 or more times a week/ almost always**
1. Having upsetting thoughts or images about your burn injury that came into your head when you didn't want them to	☐	☐	☐	☐
2. Having bad dreams or nightmares	☐	☐	☐	☐
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)	☐	☐	☐	☐
4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc)	☐	☐	☐	☐
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)	☐	☐	☐	☐
6. Trying not to think about, talk about, or have feelings about your burn injury	☐	☐	☐	☐
7. Trying to avoid activities, people, or places that remind you of your burn injury	☐	☐	☐	☐
8. Not being able to remember an important part of your burn injury	☐	☐	☐	☐
9. Having much less interest or doing things you used to do	☐	☐	☐	☐
10. Not feeling close to people around you	☐	☐	☐	☐
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy)	☐	☐	☐	☐
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)	☐	☐	☐	☐
13. Having trouble falling or staying asleep	☐	☐	☐	☐

Choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.	Not at all or only at one time	Once a week or less/ once in a while	2 to 4 times a week/ half the time	5 or more times a week/ almost always
14. Feeling irritable or having fits of anger	☐	☐	☐	☐
15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class)	☐	☐	☐	☐
16. Being overly careful (for example, checking to see who is around you and what is around you)	☐	☐	☐	☐
17. Being jumpy or easily startled (for example, when someone walks up behind you)	☐	☐	☐	☐

Section 6					
Please respond to each item by marking one box per row.					
In the past 7 days…	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost always**
1. I felt mad	☐	☐	☐	☐	☐
2. I felt upset	☐	☐	☐	☐	☐
3. I felt fed up	☐	☐	☐	☐	☐
4. I was so angry I felt like throwing something	☐	☐	☐	☐	☐
5. I was so angry I felt like yelling at somebody	☐	☐	☐	☐	☐

Section 7					
Please respond to each question or statement by marking one box per row.					
Physical Function **In the past 7 days…**	**With no trouble**	**With a little trouble**	**With some trouble**	**With a lot of trouble**	**Not able to do**
I could do sports and exercise that other kids my age could do	☐	☐	☐	☐	☐
I could get up from the floor	☐	☐	☐	☐	☐
I could walk up stairs without holding on to anything	☐	☐	☐	☐	☐
I have been physically able to do the activities I enjoy most	☐	☐	☐	☐	☐
Anxiety **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I felt like something awful might happen	☐	☐	☐	☐	☐
I felt nervous	☐	☐	☐	☐	☐
I felt worried	☐	☐	☐	☐	☐
I worried when I was at home	☐	☐	☐	☐	☐
Depressive symptoms **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I felt everything in my life went wrong	☐	☐	☐	☐	☐
I felt lonely	☐	☐	☐	☐	☐
I felt sad	☐	☐	☐	☐	☐
It was hard for me to have fun	☐	☐	☐	☐	☐

Fatigue **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
Being tired made it hard for me to keep up with my schoolwork	☐	☐	☐	☐	☐
I got tired easily	☐	☐	☐	☐	☐
I was too tired to do sports or exercise	☐	☐	☐	☐	☐
I was too tired to enjoy the things I like to do	☐	☐	☐	☐	☐
Peer relationships **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I felt accepted by other kids my age	☐	☐	☐	☐	☐
I was able to count on my friends	☐	☐	☐	☐	☐
My friends and I helped each other out	☐	☐	☐	☐	☐
Other kids wanted to be my friend	☐	☐	☐	☐	☐
Pain Interference **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I had trouble sleeping when I had pain	☐	☐	☐	☐	☐
It was hard for me to pay attention when I had pain	☐	☐	☐	☐	☐
It was hard for me to run when I had pain	☐	☐	☐	☐	☐
It was hard for me to walk one block when I had pain	☐	☐	☐	☐	☐

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

Section 8					
Indicate how much you agree or disagree:					
	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. My life is going well.	☐	☐	☐	☐	☐
2. My life is just right.	☐	☐	☐	☐	☐
3. I have a good life.	☐	☐	☐	☐	☐
4. I have what I want in life.	☐	☐	☐	☐	☐

Section 9

Currently:

1. Do you take personal responsibility for grooming when asked?
   - ☐ 1. Often
   - ☐ 2. Sometimes
   - ☐ 3. Never

Approximately how many times a month do you 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 you participate in leisure activities do you 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 you child have a best friend with whom you confide?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

Section 10						
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**
I had trouble sleeping when I was itching		☐	☐	☐	☐	☐
I felt angry when I was itching		☐	☐	☐	☐	☐
It was hard for me to pay attention when I was itching		☐	☐	☐	☐	☐
It was hard for me to have fun when I was itching		☐	☐	☐	☐	☐
	N/A (I don't do schoolwork)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
I had trouble doing schoolwork when I was itching	☐	☐	☐	☐	☐	☐

Section 11					
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 you exercise or play so hard that your body got tired?	☐	☐	☐	☐	☐
How many days did you exercise really hard for 10 minutes or more?	☐	☐	☐	☐	☐
How many days did you exercise so much that you breathed hard?	☐	☐	☐	☐	☐
How many days were you so physically active that you sweated?	☐	☐	☐	☐	☐

Section 12					
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**
I had difficulty falling asleep	☐	☐	☐	☐	☐
I slept through the night	☐	☐	☐	☐	☐
I had a problem with my sleep	☐	☐	☐	☐	☐
I had trouble sleeping	☐	☐	☐	☐	☐

Section 13					
Please respond to each question or statement by marking one box per row.					
In the past 4 weeks…	**Never**	**Rarely**	**Some. times**	**Often**	**Always**
I felt I had a strong relationship with my family	☐	☐	☐	☐	☐
I felt really important to my family	☐	☐	☐	☐	☐
I got all the help I needed from my family	☐	☐	☐	☐	☐
My family and I had fun together	☐	☐	☐	☐	☐

Section 14					
NEXT ARE SOME QUESTIONS ABOUT WAYS PEOPLE SOMETIMES CHANGE AFTER DIFFICULT EVENTS. **For each of the next statements indicate the degree to which this change happened in your life as a result of your burn injury.**					
	No change	**A little**	**Some**	**A lot**	**Don't know**
I learned how nice and helpful some people can be.	☐	☐	☐	☐	☐
I can now handle big problems better than I used to.	☐	☐	☐	☐	☐
I know what is important to me better than I used to.	☐	☐	☐	☐	☐
I understand how God works better than I used to.	☐	☐	☐	☐	☐
I feel closer to other people (friends or family) than I used to.	☐	☐	☐	☐	☐
I appreciate (enjoy) each day more than I used to.	☐	☐	☐	☐	☐
I now have a chance to do some things I couldn't do before.	☐	☐	☐	☐	☐
My faith (belief) in God is stronger than it was before.	☐	☐	☐	☐	☐
I have learned that I can deal with more things than I thought I could before.	☐	☐	☐	☐	☐
I have new ideas about how I want things to be when I grow up.	☐	☐	☐	☐	☐

Section 15

This is the last section of the survey

1. What is your current weight? (lbs)_____ ☐ I don't know

2. What is your current height? (feet/inches)_____ ☐ I don't know

3. Where are you 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 current zip code? __ __ __ __ __
☐ Not applicable (not living in U.S.) ☐ Not applicable (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

6. What is your current school status?
- ☐ 1. In school
- ☐ 2. Not in school →

If you aren'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 you hadn't already returned to school before your last research study questionnaire, but you are in school now,
What was your first date to return to school since your injury? (Please take your best guess if you don't know the exact date): _____/_____/_____

8. How many years of education have you completed? (If you have not graduated from high school, please indicate the number of years spent in school).

- ☐ 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. Are you currently receiving <u>disability</u> income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)

- ☐ 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 (please specify)_____
- ☐ 99. I don't know

If yes, are you receiving disability income due to your burn injury?

- ☐ 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. I don't know

10. Do you currently have any physical problems, such as a mobility impairment (difficulty moving your arms, legs or body)?

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

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.