BMS Pediatric Proxy 0-7 Mail Form I: 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 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.

Form I Administration:	
Who is filling out this questionnaire? (Select all that apply) ☐ 1. Mother or stepmother ☐ 2. Father or stepfather ☐ 3. Guardian ☐ 4. Other	**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	**Checklist of forms: Mark when each is complete** ☐ 1. Patient Status Form ☐ 2. Medical Record Abstraction Form ☐ 3. Form I

Burn Model System Hospital Discharge Survey: Introduction

Thank you for agreeing to participate in this study. The aim of the study is to learn about how children do after a burn injury. Your answers will help us understand the experiences of all people with burn injury. Some questions ask about what things were like before your child's burn injury, other questions are about your child's health now. 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 and your child 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 and be as accurate as possible. If you have any questions please contact us at: _____.

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

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?	☐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	☐	☐	☐	☐	☐	☐	☐

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
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:						

Pre-Injury History Section

Please answer these questions about your child's situation before the injury. Your answers will help us understand problems related to the injury. Later in the survey there will be some similar questions about after the burn injury.

Section 2

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

2. What was your child's zip code at the time of his/her burn injury? __ __ __ __ __
   - ☐ Not applicable (not living in U.S.)
   - ☐ Not applicable (homeless)

3. Who was your child living with before his/her burn injury? (Choose all that apply)
   - ☐ 4. Parent or step-parent
   - ☐ 5. Other relative (siblings, grandparents)
   - ☐ 6. Others, not part of family
   - ☐ 7. Guardian

4. Was your child enrolled in school at the time of his/her burn injury?

- ☐ 1. Yes, in school
- ☐ 2. No, not in school → *If your child was not enrolled in school* at the time of his/her burn injury, why not?
  - ☐ Not school age
  - ☐ Medical problems
  - ☐ Emotional/social reasons
  - ☐ Personal choice
  - ☐ Other
  - ☐ Not applicable (going to school)
  - ☐ I don't know

5. Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group?

- ☐ 1. Above the grade level he/she should be for his/her age
- ☐ 2. At the grade level he/she should be for his/her age
- ☐ 3. Lower than the grade level he/she should be for his/her age
- ☐ 77. Not applicable
- ☐ 99. I don't know

6. In school, has your child ever been classified as a special education student?

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

7. Before his/her burn injury, did your child 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

8. Before his/her burn injury, was your child ever told by a doctor that he/she had any of the following psychological issues (choose all that apply)?

- ☐ 0. None/no psychological issues
- ☐ 1. Depression
- ☐ 2. Bipolar disorder
- ☐ 3. Anxiety
- ☐ 4. Post-Traumatic Stress Disorder (PTSD)
- ☐ 5. Schizophrenia/psychotic disorder
- ☐ 6. Other, please explain: _____
- ☐ 99. I don't know

Section 3

1. In **the month before your child's burn injury** did he/she take prescription medication for pain on a regular basis?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

In the past 12 months…

2. 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

3. 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

4. Did your child receive psychological therapy or counseling in the last 12 months?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

Post-Injury History Section

All the questions you just answered were about the time before your child's burn injury. Next are some questions about your child and his/her burn injury.

Section 4

1. Is your child of Hispanic, Latino, or Spanish Origin?
   - ☐ 1. Yes, Hispanic, Latino, or Spanish origin
   - ☐ 2. No, not of Hispanic, Latino, or Spanish origin
   - ☐ 88. Prefer not to answer

2. What is your child's race?
   - ☐ 1. African-American or Black
   - ☐ 2. Asian
   - ☐ 3. White
   - ☐ 4. American Indian/Alaskan Native
   - ☐ 5. Native Hawaiian or Other Pacific Islander
   - ☐ 6. More than one race (please specify):_____
   - ☐ 7. Some other race (please specify):_____
   - ☐ 88. Prefer not to answer

Section 5

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

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

3. 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 (my child is too young for school)

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.

4. Approximately what was your family's total income in the last full year before your burn injury (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

5. How many people are in your household? _____

6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance 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

Section 6

Instructions: *If your child is between **3 and 7 years old**, please answer the following questions.*
*If your child is **under 3 years please skip** the next four questions.*

Indicate how much you agree or disagree:

In the four weeks before my child's burn injury…	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. My child's life was going well.	☐	☐	☐	☐	☐
2. My child's life was just right.	☐	☐	☐	☐	☐
3. My child had a good life.	☐	☐	☐	☐	☐
4. My child had what he/she wanted in life.	☐	☐	☐	☐	☐

About how long did this survey take you to complete? _____

Is there anything else you would like to tell us?

_____

_____

_____

_____

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