BMS Pediatric Self Report 14-17 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 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.

Form I Administration:		
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 young people 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 burn injury, other questions are about your 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 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: ___ ___ / ___ ___ / ___ ___

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 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	☐	☐	☐	☐	☐	☐	☐

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

Pre-Injury History Section

Please answer these questions about your 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, but about after your burn injury.

Section 2					
Indicate how much you agree or disagree:					
In the four weeks before my burn…	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. My life was going well.	☐	☐	☐	☐	☐
2. My life was just right.	☐	☐	☐	☐	☐
3. I had a good life.	☐	☐	☐	☐	☐
4. I had what I wanted in life.	☐	☐	☐	☐	☐

Section 3

During the 4 weeks before your burn:

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

Approximately how many times during the 4 weeks before the burn did you participate in the following activities outside of your home?

2. Shopping
   - ☐ 1. Never
   - ☐ 2. 1-4 times
   - ☐ 3. 5 or more times

3. Leisure activities such as movies, sports, and restaurants.
   - ☐ 1. Never
   - ☐ 2. 1-4 times
   - ☐ 3. 5 or more times

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

During the 4 weeks before your burn:

5. When you participated in leisure activities did you usually do this alone or with others?
   - ☐ 1. Mostly alone
   - ☐ 3. Mostly with family members
   - ☐ 4. Mostly with friends
   - ☐ 5. With a combination of family and friends
   - ☐ 77. Not applicable (no leisure activities)

6. Did you have a best friend with whom you confided?
   - ☐ 1. Yes
   - ☐ 2. No

Section 4

1. In **the month before** your burn injury did you 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 you take medication for being worried, tense, or anxious?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

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

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

Section 5

1. Before your burn injury, where were you living? (Choose only one)
   - ☐ 1. Private residence
   - ☐ 2. Nursing home
   - ☐ 3. Adult home
   - ☐ 4. Correctional institution
   - ☐ 5. Hotel/motel
   - ☐ 6. Homeless
   - ☐ 7. Hospital

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

3. Who were you living with before your 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. Were you enrolled in school at the time of your burn injury?

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

5. Are you ahead, at the same level, or behind the grade you should be in for your age group?

- ☐ 1. Above the grade level I should be in for my age
- ☐ 2. At the grade level I should be in for my age
- ☐ 3. Lower than the grade level I should be in for my age
- ☐ 77. Not applicable
- ☐ 99. I don't know

6. In school, have you ever been classified as a special education student?

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

7. Before your burn injury, did you 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 your burn injury, were you ever told by a doctor that you 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

Post-Injury History Section

All the questions you just answered were about the time before your burn injury. Next are some questions about you and your burn injury. As a reminder, some of these questions can feel repetitive but it's part of the research process. Thank you for your patience.

Section 6

In the past 7 days, or since your burn if you were injured less than 7 days ago…

How would you rate your pain on average?...

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0	1	2	3	4	5	6	7	8	9	10
No pain										**Worst pain imaginable**

Section 7

1. Are you 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 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 8

This is the last section of the survey

1. After your hospital discharge, where are/will you be living? (Choose only one)
   - ☐ 1. Private residence
   - ☐ 2. Nursing home
   - ☐ 4. Correctional institution
   - ☐ 5. Hotel/motel
   - ☐ 6. Homeless
   - ☐ 7. Hospital
   - ☐ 99. I don't know

2. Who will you 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
- ☐ 99. I don't know

3. 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. If you have at least a high school diploma, please indicate the highest degree earned or worked toward post-high school. In other words, what is the highest level of education you have 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

4. 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

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.