

BMS Pediatric Proxy 0-7 Interview Form I: Research Staff Instructions

Instructions: This form is designed to aid in the interview process. If you are handing the form to the participant for them to fill out, use the mail version of this form instead.

Instructions to the interviewer appear throughout the survey in italics, and scripts to read aloud to the participants appear using quotation marks. The scripts to read aloud are also boxed and shaded in light gray. Use these scripts as suggestions for how to move through the survey while establishing rapport with the participant.

Missing codes appear throughout this interview in small boxes. If a participant doesn't want to answer any item or doesn't know the answer, circle "88" (Declined to Answer/Refused) or "99" (Unknown) in that item's corresponding missing code box. Some items have missing codes built into their response options and therefore don't have those code boxes.

Form I Administration:	
Who is responding to this questionnaire? (Select all that apply) <input type="checkbox"/> 1. Mother or stepmother <input type="checkbox"/> 2. Father or stepfather <input type="checkbox"/> 3. Guardian <input type="checkbox"/> 4. Other	What is the method of administration of this form? <input type="checkbox"/> 1. In person interview <input type="checkbox"/> 3. Telephone interview <input type="checkbox"/> 5. Medical Record Review
What is the language of administration of this form? <input type="checkbox"/> 1. English <input type="checkbox"/> 2. Spanish	Checklist of forms: Mark when each is complete <input type="checkbox"/> 1. Patient Status Form <input type="checkbox"/> 2. Medical Record Abstraction Form <input type="checkbox"/> 3. Form I

Introduction script (Replace this script with your personalized center introduction script if applicable or modify as needed to facilitate the flow and rapport of the interview):

"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 and I appreciate your willingness to share those experiences. I'll be asking questions about your child's burn injury, his/her health, and other questions about him/her and people around him/her. Some questions ask about what things were like before your child's burn injury, other questions are about his/her health now. I will guide you as we go along. 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. Just tell me, "skip." Please let me know at any time if you have any questions."

Burn Model System Hospital Discharge Survey

Today's Date: ____ / ____ / ____

“We’re going to go ahead and get started.”

Interviewer instructions: Write in 88 for refused or 99 for unknown for this section.

Section I

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. Seeing?	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. with Growth?	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. with Pain?	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If yes, specify problem:		

Pre-Injury History Section

“The next section of questions is 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	
<p>1. Before your child’s burn injury, where was he/she living? (Choose only one)</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 80%;"> <input type="checkbox"/> 1. Private residence <input type="checkbox"/> 2. Nursing home <input type="checkbox"/> 4. Correctional institution <input type="checkbox"/> 5. Hotel/motel <input type="checkbox"/> 6. Homeless <input type="checkbox"/> 7. Hospital </div> <div style="width: 15%; text-align: right;"> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div> </div> </div>	
<p>2. What was your child’s zip code at the time of his/her burn injury? _____</p> <div style="display: flex; justify-content: space-between;"> <input type="checkbox"/> Not applicable (not living in U.S.) <input type="checkbox"/> Not applicable (homeless) <small>(code 99999 for unknown)</small> </div>	
<p>3. Who was your child living with before his/her burn injury? (Choose all that apply)</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 80%;"> <input type="checkbox"/> 4. Parent or step-parent <input type="checkbox"/> 5. Other relative (siblings, grandparents) <input type="checkbox"/> 6. Others, not part of family <input type="checkbox"/> 7. Guardian </div> <div style="width: 15%; text-align: right;"> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div> </div> </div>	
<p>4. Was your child enrolled in school at the time of his/her burn injury?</p> <div style="display: flex; align-items: center;"> <div style="width: 40%;"> <input type="checkbox"/> 1. Yes, in school <input type="checkbox"/> 2. No, not in school </div> <div style="width: 10%; text-align: center; font-size: 2em;">→</div> <div style="width: 45%;"> <p><i>If your child was not enrolled in school at the time of his/her burn injury, why not?</i></p> <input type="checkbox"/> Not school age <input type="checkbox"/> Medical problems <input type="checkbox"/> Emotional/social reasons <input type="checkbox"/> Personal choice <input type="checkbox"/> Other <input type="checkbox"/> Not applicable (going to school) <input type="checkbox"/> I don’t know </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 20px;"> <div style="width: 40%;"> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div> </div> <div style="width: 15%; text-align: right;"> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> </div> </div>	
<p>5. Is he/she ahead, at the same level, or behind what grade he/she should be in for his/her age group?</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 80%;"> <input type="checkbox"/> 1. Above the grade level he/she should be for his/her age <input type="checkbox"/> 2. At the grade level he/she should be for his/her age <input type="checkbox"/> 3. Lower than the grade level he/she should be for his/her age <input type="checkbox"/> 77. Not applicable <input type="checkbox"/> 99. I don’t know </div> <div style="width: 15%; text-align: right;"> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> </div> </div>	
<p>6. In school, has your child ever been classified as a special education student?</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 80%;"> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 77. Not applicable <input type="checkbox"/> 99. I don’t know </div> <div style="width: 15%; text-align: right;"> <div style="border: 1px solid black; padding: 2px;">88/Refused</div> </div> </div>	

<p>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)?</p> <p> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know </p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
<p>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)?</p> <p> <input type="checkbox"/> 0. None/no psychological issues <input type="checkbox"/> 1. Depression <input type="checkbox"/> 2. Bipolar disorder <input type="checkbox"/> 3. Anxiety <input type="checkbox"/> 4. Post-Traumatic Stress Disorder (PTSD) <input type="checkbox"/> 5. Schizophrenia/psychotic disorder <input type="checkbox"/> 6. Other, please explain: _____ <input type="checkbox"/> 99. I don't know </p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>

Section 3

<p>1. In the month before your child's burn injury did he/she take <u>prescription</u> medication for pain on a regular basis?</p> <p> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know </p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
In the past 12 months...	
<p>2. In the past 12 months, did your child take medication for being worried, tense, or anxious?</p> <p> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know </p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
<p>3. In the past 12 months, did your child take medication for being sad, empty, or depressed?</p> <p> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know </p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>
<p>4. Did your child receive psychological therapy or counseling in the last 12 months?</p> <p> <input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 99. I don't know </p>	<div style="border: 1px solid black; padding: 2px; display: inline-block;">88/Refused</div>

Post-Injury History Section

“All the questions you just answered were about your child and the time before your child’s burn injury. Next I have some some questions about your child and his/her situation after his/her burn injury.”

Section 4

1. Is your child of Hispanic, Latino, or Spanish Origin? <input type="checkbox"/> 1. Yes, Hispanic, Latino, or Spanish origin <input type="checkbox"/> 2. No, not of Hispanic, Latino, or Spanish origin <input type="checkbox"/> 88. Prefer not to answer	<div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
2. What is your child’s race? <input type="checkbox"/> 1. African-American or Black <input type="checkbox"/> 2. Asian <input type="checkbox"/> 3. White <input type="checkbox"/> 4. American Indian/Alaskan Native <input type="checkbox"/> 5. Native Hawaiian or Other Pacific Islander <input type="checkbox"/> 6. More than one race (please specify): _____ <input type="checkbox"/> 7. Some other race (please specify): _____ <input type="checkbox"/> 88. Prefer not to answer	<div style="border: 1px solid black; padding: 2px;">99/Unknown</div>

Section 5

1. After your child’s hospital discharge, where is/will he/she be living? (Choose only one) <input type="checkbox"/> 1. Private residence <input type="checkbox"/> 2. Nursing home <input type="checkbox"/> 4. Correctional institution <input type="checkbox"/> 5. Hotel/motel <input type="checkbox"/> 6. Homeless <input type="checkbox"/> 7. Hospital	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
2. Who will your child be living with after hospital discharge? (Choose all that apply) <input type="checkbox"/> 4. Parent or step-parent <input type="checkbox"/> 5. Other relative (siblings, grandparents) <input type="checkbox"/> 6. Others, not part of family <input type="checkbox"/> 7. Guardian	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>
3. How many years of education has your child completed? <input type="checkbox"/> 0. Preschool completed <input type="checkbox"/> 1. 1 year or less <input type="checkbox"/> 2. 2 years <input type="checkbox"/> 3. 3 years <input type="checkbox"/> 4. 4 years <input type="checkbox"/> 77. N/A, not school age	<div style="border: 1px solid black; padding: 2px;">88/Refused</div> <div style="border: 1px solid black; padding: 2px;">99/Unknown</div>

“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)

99/Unknown

- ☐ 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? _____

88/Refused

99/Unknown

6. Is your child currently receiving disability income such as Social Security Disability or Private Long Term Insurance disability? (Choose all that apply)

88/Refused

99/Unknown

- ☐ 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

Interviewer Instructions: *If the child is between 3 and 7 years old, please ask the following questions. Otherwise skip this section. Write in 88 for refused or 99 for unknown for this section.*

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.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. My child’s life was just right.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My child had a good life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. My child had what he/she wanted in life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Length of interview: _____

“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!”