BMS Adult 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

- ☐ 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
- ☐ 7. 20 year follow-up
- ☐ 8. 25 year follow-up

What is the method of administration of this form?

- ☐ 1. In person interview
- ☐ 3. Telephone interview
- ☐ 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. The aim of the study is to learn about how 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. 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: _____. Your last research study questionnaire was completed on ___/____/_____.

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

Section 1

1. What is your primary mode of transportation?
   - ☐ 1. Driving my own vehicle
   - ☐ 2. Riding with someone else
   - ☐ 3. Public transit
   - ☐ 4. Not applicable (I don't use motorized transport)

2. 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

3. 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

4. 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
- ☐ 99. I don't know

Examples of occupational therapy include helping with adaptive equipment and work environment after an 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 #9 on page 4

5. *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 #9 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?

6. At the burn center?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 77. Not applicable (no OT/PT received)
- ☐ 99. I don't know

7. At any other facility?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 77. Not applicable (no OT/PT received)
- ☐ 99. I don't know

8. 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

9. 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	
Please answer each question as it relates to your <u>current</u> health **Do you currently have:**	
1. Hearing loss?	☐ Yes ☐ No ☐ Don't know
2. Change in voice?	☐ Yes ☐ No ☐ Don't know
3. Vision problems not corrected by glasses or contact lenses?	☐ Yes ☐ No ☐ Don't know
4. Eyelid problems?	☐ Yes ☐ No ☐ Don't know
5. Excessive tearing of the eyes?	☐ Yes ☐ No ☐ Don't know
6. Difficulty with memory?	☐ Yes ☐ No ☐ Don't know
7. Difficulty with thought processing?	☐ Yes ☐ No ☐ Don't know
8. Numbness, pins and needles or burning sensations in your burn scar?	☐ Yes ☐ No ☐ Don't know
9. Numbness, pins and needles or burning sensations in your hands?	☐ Yes ☐ No ☐ Don't know
10. Numbness, pins and needles or burning sensations in your feet?	☐ Yes ☐ No ☐ Don't know
11. Trouble with your balance?	☐ Yes ☐ No ☐ Don't know
12. Varicose veins?	☐ Yes ☐ No ☐ Don't know
13. Swollen feet or legs?	☐ Yes ☐ No ☐ Don't know
14. Swollen hands or arms?	☐ Yes ☐ No ☐ Don't know
15. Difficulty breathing when doing your regular daily activities?	☐ Yes ☐ No ☐ Don't know
16. Skin cancer?	☐ Yes ☐ No ☐ Don't know
17. Joint pain?	☐ Yes ☐ No ☐ Don't know
18. Have you been pregnant or fathered a child since your last research study questionnaire?	☐ Yes ☐ No ☐ Don't know
19. Blood clots in legs or lungs?	☐ Yes ☐ No ☐ Don't know
20. Cold intolerance?	☐ Yes ☐ No ☐ Don't know
21. Excessive sweating?	☐ Yes ☐ No ☐ Don't know
22. Difficulty in hot environments?	☐ Yes ☐ No ☐ Don't know
23. Is your skin more sensitive than before your burn?	☐ Yes ☐ No ☐ Don't know

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		
In the past 7 days…		
How intense was your itch in general?.....	☐0=0 No itch → ☐1=1 ☐2=2 ☐3=3 ☐4=4 ☐5=5 ☐6=6 ☐7=7 ☐8=8 ☐9=9 ☐10=10 Worst imaginable itch	*If you did not have any itch in the past 7 days, skip to Section 5 on page 7.* *If you did have itch in the past 7 days, continue on with the rest of Section 4 on the next page.*

Section 4, continued…					
Please respond to each question or statement by marking one box per row					
In the past 7 days…	**Never**	**Rarely**	**Some-times**	**Often**	**Almost Always**
because of itch, it was hard to work……	☐	☐	☐	☐	☐
because of itch, it was hard to do even simple tasks……	☐	☐	☐	☐	☐
because of itch, I made more mistakes than normal……	☐	☐	☐	☐	☐
because of itch, it was hard to watch television……..	☐	☐	☐	☐	☐
Please respond to each question or statement by marking one box per row					
In the past 7 days…	**Never**	**Rarely**	**Some-times**	**Often**	**Almost Always**
because of itch, I felt miserable……	☐	☐	☐	☐	☐
because of itch, I felt sad……	☐	☐	☐	☐	☐
because of itch, I was restless……	☐	☐	☐	☐	☐
because of itch, I had difficulty falling asleep….	☐	☐	☐	☐	☐

Section 5					
Please respond to each question or statement by marking one box per row.					
	Excellent	**Very good**	**Good**	**Fair**	**Poor**
In general, would you say your health is:…	☐	☐	☐	☐	☐
In general, would you say your quality of life is:……	☐	☐	☐	☐	☐
In general, how would you rate your physical health?……	☐	☐	☐	☐	☐
In general, how would you rate your mental health, including your mood and your ability to think?……	☐	☐	☐	☐	☐
In general, how would you rate your satisfaction with your social activities and relationships?……	☐	☐	☐	☐	☐
In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)……	☐	☐	☐	☐	☐
	Completely	**Mostly**	**Moderately**	**A little**	**Not at all**
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?……	☐	☐	☐	☐	☐
In the past 7 days…	**Never**	**Rarely**	**Some-times**	**Often**	**Always**
How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?……	☐	☐	☐	☐	☐
In the past 7 days…	**None**	**Mild**	**Moderate**	**Severe**	**Very Severe**
How would you rate your fatigue on average?……	☐	☐	☐	☐	☐

Section 6					
Please respond to each question or statement by marking one box per row.					
Physical Function	**Without any difficulty**	**With a little difficulty**	**With some difficulty**	**With much difficulty**	**Unable to do**
Are you able to do chores such as vacuuming or yard work?	☐	☐	☐	☐	☐
Are you able to go up and down stairs at a normal pace?	☐	☐	☐	☐	☐
Are you able to go for a walk of at least 15 minutes?	☐	☐	☐	☐	☐
Are you able to run errands and shop?	☐	☐	☐	☐	☐
Anxiety **In the past 7 days…**	**Never**	**Rarely**	**Some-times**	**Often**	**Always**
I felt fearful……..	☐	☐	☐	☐	☐
I found it hard to focus on anything other than my anxiety……..	☐	☐	☐	☐	☐
My worries overwhelmed me……	☐	☐	☐	☐	☐
I felt uneasy……	☐	☐	☐	☐	☐
Depression **In the past 7 days…**	**Never**	**Rarely**	**Some-times**	**Often**	**Always**
I felt worthless……	☐	☐	☐	☐	☐
I felt helpless……..	☐	☐	☐	☐	☐
I felt depressed……	☐	☐	☐	☐	☐
I felt hopeless……	☐	☐	☐	☐	☐
Fatigue **During the past 7 days…**	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
I feel fatigued……..	☐	☐	☐	☐	☐
I have trouble starting things because I am tired……	☐	☐	☐	☐	☐

In the past 7 days…	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
How run down did you feel on average?...	☐	☐	☐	☐	☐
How fatigued were you on average?.....	☐	☐	☐	☐	☐
Sleep Disturbance **In the past 7 days…**	**Very poor**	**Poor**	**Fair**	**Good**	**Very good**
My sleep quality was…….	☐	☐	☐	☐	☐
In the past 7 days…	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
My sleep was refreshing……	☐	☐	☐	☐	☐
I had a problem with my sleep…….	☐	☐	☐	☐	☐
I had difficulty falling asleep……	☐	☐	☐	☐	☐
Ability to Participate in Social Roles and Activities	**Never**	**Rarely**	**Some-times**	**Usually**	**Always**
I have trouble doing all of my leisure activities with others…….	☐	☐	☐	☐	☐
I have trouble doing all of the family activities that I want to do……	☐	☐	☐	☐	☐
I have trouble doing all of my usual work (include work at home)…….	☐	☐	☐	☐	☐
I have trouble doing all of the activities with friends that I want to do……	☐	☐	☐	☐	☐
Pain Interference **In the past 7 days…**	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
How much did pain interfere with your day to day activities?……	☐	☐	☐	☐	☐
How much did pain interfere with work around the home? …….	☐	☐	☐	☐	☐
How much did pain interfere with your ability to participate in social activities? …	☐	☐	☐	☐	☐
How much did pain interfere with your household chores? …….	☐	☐	☐	☐	☐

Pain Intensity In the past 7 days…											
How would you rate your pain on average?...	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
	0	1	2	3	4	5	6	7	8	9	10
	No pain										**Worst pain imaginable**

In order to understand if and how a burn injury changes people's satisfaction with their sex life, we ask a few questions about sexual function. Everybody can answer these questions. If you did not have any sexual activity in the past 30 days, please rate how satisfied you are with no sexual activity.

Please respond to each item by marking one box per row.

In the past 30 days…	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very**
How satisfied have you been with your sex life?……..	☐	☐	☐	☐	☐
In the past 30 days…	**None**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
How much pleasure has your sex life given you?……	☐	☐	☐	☐	☐

*INSTRUCTIONS: If you **had a hand burn**, please complete the next 4 questions. If you **did NOT have a hand burn**, please move on to Section 7 on the next page.*

Please respond to each item by marking one box per row.

Upper Extremity	**Without any difficulty**	**With a little difficulty**	**With some difficulty**	**With much difficulty**	**Unable to do**
Are you able to cut your food using utensils? ……..	☐	☐	☐	☐	☐
Are you able to open a can with a hand can opener? ……..	☐	☐	☐	☐	☐
Are you able to button your shirt? …….	☐	☐	☐	☐	☐
Are you able to pick up coins from a table top? ……..	☐	☐	☐	☐	☐

Section 7					
Please respond to each question or statement by marking one box per row.					
Lately…	**Never**	**Rarely**	**Some-times**	**Often**	**Always**
1. Because of my injury, some people avoided me.	☐	☐	☐	☐	☐
2. Because of my injury, I felt left out of things.	☐	☐	☐	☐	☐
3. Because of my injury, people avoided looking at me.	☐	☐	☐	☐	☐
4. I felt embarrassed about my injury.	☐	☐	☐	☐	☐
5. Because of my injury, some people seemed uncomfortable with me.	☐	☐	☐	☐	☐
6. I felt embarrassed because of my physical limitations.	☐	☐	☐	☐	☐
7. Because of my injury, people were unkind to me.	☐	☐	☐	☐	☐
8. Some people acted as though it was my fault I have this injury.	☐	☐	☐	☐	☐

Section 8				
Please answer thinking of your burn wounds/scars RIGHT NOW				
How bothered are you about…	**Not at all**	**A little**	**Quite a bit**	**A lot**
…how your wounds/scars look when they are not covered up (for example without clothes or makeup)?	☐	☐	☐	☐
…how noticeable your wounds/scars are to other people?	☐	☐	☐	☐
…how your wounds/scars look overall?	☐	☐	☐	☐

Section 9		
This section asks about alcohol use in the past year (Or, since your last research study questionnaire, if your burn was less than a year ago). *If you did not drink alcohol in the past year,* ***mark this box*** ☐ *and then skip to Section 10, below*		
In the past year…(*Or,* since your last research study questionnaire, *if your burn was less than a year ago*).		
1. Have you felt you needed to cut down on your drinking?	☐ Yes	☐ No
2. Have people annoyed you by criticizing your drinking?	☐ Yes	☐ No
3. Have you ever felt guilty about drinking?	☐ Yes	☐ No
4. Have you ever felt you needed a drink first thing in the morning (eye-opener) to steady your nerves or to get rid of a hangover?	☐ Yes	☐ No
Section 10		
This section asks about drug use in the past year (Or, since your last research study questionnaire, if your burn was less than a year ago). *If you did not use drugs in the past year,* ***mark this box*** ☐ *and then skip to Section 11 on the next page*		
The questions in this section are asking about use of drugs like crack or heroin; or about prescription drugs like pain killers or stimulants that were not prescribed to you; or chemicals you might have inhaled or 'huffed'. We also want to know if sometimes you took more than you should have of any drugs that have been prescribed to you.		
In the past year…(*Or,* since your last research study questionnaire, *if your burn was less than a year ago*)		
1. Have you felt you needed to cut down on your drug use?	☐ Yes	☐ No
2. Have people annoyed you by criticizing your drug use?	☐ Yes	☐ No
3. Have you ever felt guilty about your drug use?	☐ Yes	☐ No
4. Have you ever felt you needed to use drugs first thing in the morning (eye-opener) to steady your nerves or to get rid of a hangover?	☐ Yes	☐ No

Section 11

Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then mark circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

In the past month, how much were you bothered by:	**Not at all**	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Repeated, disturbing, and unwanted memories of the stressful experience?	**0**	**1**	**2**	**3**	**4**
2. Repeated, disturbing dreams of the stressful experience?	**0**	**1**	**2**	**3**	**4**
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	**0**	**1**	**2**	**3**	**4**
4. Feeling very upset when something reminded you of the stressful experience?	**0**	**1**	**2**	**3**	**4**
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	**0**	**1**	**2**	**3**	**4**
6. Avoiding memories, thoughts, or feelings related to the stressful experience?	**0**	**1**	**2**	**3**	**4**
7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	**0**	**1**	**2**	**3**	**4**
8. Trouble remembering important parts of the stressful experience?	**0**	**1**	**2**	**3**	**4**
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	**0**	**1**	**2**	**3**	**4**
10. Blaming yourself or someone else for the stressful experience or what happened after it?	**0**	**1**	**2**	**3**	**4**
11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?	**0**	**1**	**2**	**3**	**4**
12. Loss of interest in activities that you used to enjoy?	**0**	**1**	**2**	**3**	**4**
13. Feeling distant or cut off from other people?	**0**	**1**	**2**	**3**	**4**
14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	**0**	**1**	**2**	**3**	**4**

In the past month, how much were you bothered by:	Not at all	A little bit	Moderately	Quite a bit	Extremely
15. Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17. Being "superalert" or watchful or on guard?	0	1	2	3	4
18. Feeling jumpy or easily startled?	0	1	2	3	4
19. Having difficulty concentrating?	0	1	2	3	4
20. Trouble falling or staying asleep?	0	1	2	3	4

Section 12

Currently:

1. Who usually looks after your personal finances, such as banking and paying bills?
   - ☐ 1. Yourself alone
   - ☐ 2. Yourself and someone else
   - ☐ 3. Someone else

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 have a best friend with whom you confide?
   - ☐ 1. Yes
   - ☐ 2. No
   - ☐ 99. I don't know

Section 13

Here are 4 statements with which you may agree or disagree. Using a scale where 1 represents you strongly disagree and 7 represents that you strongly agree, indicate your agreement with each item by the appropriate choice Please be open and honest in your response.

	Strongly disagree =1	Disagree =2	Slightly disagree =3	Neither agree nor disagree =4	Slightly agree =5	Agree =6	Strongly agree =7
1. In most ways my life is close to ideal:	☐	☐	☐	☐	☐	☐	☐
2. The conditions of my life are excellent:	☐	☐	☐	☐	☐	☐	☐
3. I am satisfied with my life:	☐	☐	☐	☐	☐	☐	☐
4. So far, I have gotten the important things I want in life:	☐	☐	☐	☐	☐	☐	☐

Section 14

These are some questions about ways people sometimes change after difficult events. Indicate for each of the next statements the degree to which this change occurred in your life as a result of your burn injury, using these response categories:
0 = I did not experience this change as a result of my burn injury
1 = I experienced this change to a very small degree as a result of my burn injury
2 = I experienced this change to a small degree as a result of my burn injury
3 = I experienced this change to a moderate degree as a result of my burn injury
4 = I experienced this change to a great degree as a result of my burn injury
5 = I experienced this change to a very great degree as a result of my burn injury

	I did not exper-ience this change	**To a very small degree**	**To a small degree**	**To a moderate degree**	**To a great degree**	**To a very great degree**
1. I changed my priorities about what is important in life.	☐	☐	☐	☐	☐	☐
2. I have a greater appreciation for the value of my own life.	☐	☐	☐	☐	☐	☐
3. I am able to do better things with my life.	☐	☐	☐	☐	☐	☐
4. I have a better understanding of spiritual matters.	☐	☐	☐	☐	☐	☐
5. I have a greater sense of closeness with others.	☐	☐	☐	☐	☐	☐

	I did not exper-ience this change	To a very small degree	To a small degree	To a moderate degree	To a great degree	To a very great degree
6. I established a new path for my life.	☐	☐	☐	☐	☐	☐
7. I know better that I can handle difficulties.	☐	☐	☐	☐	☐	☐
8. I have a stronger religious faith.	☐	☐	☐	☐	☐	☐
9. I've discovered that I'm stronger than I thought I was.	☐	☐	☐	☐	☐	☐
10. I learned a great deal about how wonderful people are.	☐	☐	☐	☐	☐	☐

Section 15

Please respond to all questions. Please mark one box per row.

Please rate how well each statement describes you right now.	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
1. I maintain a positive outlook even in bad circumstances.	☐	☐	☐	☐	☐
2. When something happens that makes me feel stressed, I usually calm down quickly.	☐	☐	☐	☐	☐
3. When something stressful happens, I keep going.	☐	☐	☐	☐	☐
4. When things go wrong in my life, I can pick myself up and start again.	☐	☐	☐	☐	☐

Section 16

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
- ☐ 3. Adult 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)
- ☐ 1. Alone
- ☐ 2. Spouse/partner/significant other
- ☐ 3. Friend
- ☐ 4. Parent or step-parent
- ☐ 5. Other relative (siblings, grandparents)
- ☐ 6. Others, not part of family
- ☐ 7. Guardian
- ☐ 8. Young children
- ☐ 9. Adult children
- ☐ 99. I don't know

6. What is your current marital status? (Choose only one)
- ☐ 1. Married; living common-law or with a partner
- ☐ 2. Separated
- ☐ 3. Divorced
- ☐ 4. Widowed
- ☐ 5. Single (not married)

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.

7. 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

8. How many people are in your household? _____

9. In the past year, how many months did you work for pay? _____(*fill in # of months*)

- ☐ Don't know

10. What is your primary occupation (*or* what was your primary occupation the last time you worked, *if the answer to the above was less than 1 month)*?

Occupation: _____ (*not name of company*)

Occupation Categories [for staff use only]
1 - Executive, Administrative, And Managerial, 2 - Professional Specialty, 3 - Technicians And Related Support , 4 – Sales, 5 - Administrative Support Including Clerical, 6 - Private Household, 7 - Protective Service, 8 - Service, Except Protective And Household, 9 - Farming, Forestry, And Fishing, 10 - Precision Production, Craft, And Repair, 11 - Machine Operators, Assemblers, And Inspectors, 12 - Transportation And Material Moving, 13 - Handlers, Equipment Cleaners, Helpers, And Laborers, 14 - Military Occupations

11. What is your current employment status? (Choose only one)

- ☐ 1. Working
- ☐ 2. Not working (looking for work)
- ☐ 3. Not working (not looking for work)
- ☐ 4. Homemaker/caregiver
- ☐ 5. Volunteer
- ☐ 6. Retired

(*If you are working*) About how many hours a week do you work for pay?

_____
(fill in # of hours)

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

____/_____/_____

If you are not currently working, skip to #14, below.

12. *(If you are currently working,)* Have you received any work accommodations from your employer due to your burn injury? This could include a change in procedure or schedule, a modification to your work site, or assistive equipment.

- ☐ 1. No, my employer was not asked for accommodations and I did not receive any
- ☐ 2. No, my employer was asked for accommodations, but the request was denied
- ☐ 3. Yes, my employer was asked for accommodations and I received some or all accommodations asked for
- ☐ 4. Yes, my employer provided accommodations without being asked.
- ☐ 99. I don't know

13. Approximately what was your individual income for the past full year? (in U.S. dollars)

- ☐ 1. Less than $25,000
- ☐ 2. $25,000-$40,999
- ☐ 3. $41,000-$55,999
- ☐ 4. $56,000-$70,999
- ☐ 5. $71,000-$85,999
- ☐ 6. $86,000-$100,000
- ☐ 7. Greater than $100,000
- ☐ 8. Living outside the United States
- ☐ 77. Not applicable (no individual income)
- ☐ 88. Prefer not to answer

14. What is your current school status?

- ☐ 1. In school
- ☐ 2. Not in school →

If you are not working or going to school, why not?

- ☐ Not applicable (working or going to school)
- ☐ Burn related
- ☐ Other medical problems
- ☐ Problems with employer
- ☐ Emotional/social reasons
- ☐ Legal reasons/jail
- ☐ Substance abuse
- ☐ Personal choice
- ☐ Other
- ☐ Retired
- ☐ Homemaker/caregiver
- ☐ Unemployed but actively seeking employment
- ☐ I don't know

15. 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)
- ☐ 13. Work towards Associate's degree, vocational degree, or trade school diploma/cert.
- ☐ 14. Associate's degree, vocational degree, or trade school diploma/certificate
- ☐ 15. Work towards Bachelor's degree
- ☐ 16. Bachelor's degree
- ☐ 17. Work towards Master's degree
- ☐ 18. Master's degree
- ☐ 19. Work towards doctorate level degree
- ☐ 20. Doctoral level degree

16. 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

17. 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

18. Who is the primary sponsor of your care currently, or who is paying for the majority of your 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

19. Have you ever served in the military?

- ☐ 1. No
- ☐ 2. Yes

About 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.