**APPENDIX 1**

**On-line script for screening:**

The pediatric intensive care unit (PICU) commonly sees children who are undergoing a life threatening illness (critical illness). A life threatening illness can result in loss of consciousness. For instance, one reason for loss of consciousness may be brought on by the heart temporarily stopping (cardiac arrest). Some adults and children alike who have gained consciousness after experiencing a life threatening illness may report memories, experiences, and awareness during unconsciousness. These so called near death experiences, may include peaceful feelings, a perception of a tunnel and/or a light, seeing relatives, a life review, and positive emotions. However, studies that explore these types of memories and awareness during loss of consciousness at the time of life threatening illness are limited to adults. There are very few studies that explore this aspect of a life threatening illness among children. This study aims to determine the prevalence of memories, experiences, and awareness, and so called near death experiences, among children under the age of 18 who survived a life threatening illness which may have resulted in loss of consciousness.

Specifically, we are interested in learning more about your child’s memories, experiences, and awareness (i.e.; peaceful feelings, a perception of a tunnel and/or a light, seeing relatives, a life review, and positive emotions, etc.) during their time in pediatric critical care. More information is needed from children who have experienced a life threatening illness in order to better understand children’s memories and experiences during time of unconsciousness. Your contribution will help the research community develop a better understanding of children’s unique experiences during their time in the pediatric intensive care unit, which may lead to recommendations for improvement in the quality of care for this population.

Before we can enroll your child in the study, we need to determine your child’s eligibility. You will need to complete a few questions which should only take 5 minutes of your time. If your child is eligible to participate in this study, we will provide more information about the study and you will be able to continue onto the next section. Once you have completed the questionnaire and have been informed that your child is eligible for the study you will be asked to leave your contact information so that a research team member at New York University (NYU) Langone Health, University Hospital Southampton and other participating sites can reach out to you and schedule an interview. You are in no way obligated to complete the following screening questionnaire. If you choose not to complete the screening questionnaire no one will know. If you complete the screening questionnaire and wish to not be contacted by an NYU research staff member, simply do not enter your contact information at the completion of the questionnaire.

You can call NYU Langone Research Staff at <insert contact number> with any questions about this study. If you have any questions regarding your rights as a research subject, please contact the New York University School of Medicine Institutional Review Board at (212)263-4110.

If you received information regarding this study from a participating site in the United Kingdom please check the respective box below to receive the appropriate contact information that you may refer to with any questions you may have.

<insert list of UK Sites>

If you are interested in completing the screening questionnaire for this study please proceed to the next section.

**Thank you for your participation!**

1. **Online-Screening Tool**

**I understand that my participation in this study is for research purposes and my participation is voluntary.**

1. Are you a parent or legal guardian of a child who survived a life threatening illness?

Yes  No

1. Is your child currently under the age of 18?

Yes  No

1. Did your child’s life threatening illness result in loss of consciousness?

Yes  No

1. Did your child’s loss of consciousness result in the heart temporarily stopping (cardiac arrest)?

Yes  No

1. Is your child in a persistent state of unconsciousness or coma to this day?

Yes  No

1. Did your child report some level of memories and/or experiences (i.e.; peaceful feelings, a perception of a tunnel and/or a light, seeing relatives, a life review, and positive emotions, etc.) during their life threatening illness?

Yes  No

Scoring Instructions:

* Participants who report **no** to questions’ a, b, c, f will **NOT** be eligible to participate in the study.
* Participants who report **yes** to question e will **NOT** be eligible to participate in the study.

-Participants who respond **yes** to questions’ a, b, c, f, or **no to question e** will see the text below and will be asked to leave their contact information for a research team member to contact them.

Thank you for taking the time to complete the screening questionnaire. Your child has been determined eligible for the Interview Phase of this study. Please enter your contact information below for one of our research team members to contact you with further information regarding this study or please contact the research team directly at [<enter](mailto:Resuscitationlab@nyulangone.org) email address here> or <enter phone number here>.

Please enter your first and last name: \_\_\_\_\_\_\_\_\_\_

Please enter you email address: \_\_\_\_\_\_\_\_\_\_\_\_

Please enter your phone number: \_\_\_\_\_\_\_\_\_\_\_

**Thank you!**

**APPENDIX 2A**

**Questionnaire A: Demographics, clinical and social support information**

This assessment was developed by the NYU Langone Health research team and is being carried out at participating sites in the United States and United Kingdom. Basic demographic and clinical information will be collected. These data will be obtained directly from the child’s parents. It will be entered and stored securely in the study data capture system (REDCap).

*Instructions: Please answer the following questions.*

1. What is your name (Parent/Legal Guardian Name)? \_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_

First Last

2. What is your child’s current age? Drop Down Menu \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

3. What was your child’s age (years) when he/she was hospitalized due to a life threatening illness? Drop Down Menu \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

4. What is your child’s race and ethnicity?

Hispanic or Latino

Black or African American

Asian

White

American Indian or Alaska Native

Native Hawaiian or Other Pacific Islander

Two or more races

Other (Scroll down)

Unknown

5. What is your child’s gender?

Female

Male

Other (Specify) \_\_\_\_\_\_\_

6. What is your family’s religion?

Christianity

Islam

Buddhism

Hinduism

Judaism

Non-Religious

Other (scroll down)

7. Where do you live?

United States

United Kingdom

Other (Scroll down)

1. What was the approximate Month and Year of your child’s hospitalization? \_\_\_/\_\_\_

Month Year

1. What was the approximate duration of your child’s time in the pediatric intensive care unit (PICU)?

≤ 1 day

2 - 3 days

4 - 8 days

9 - 30 days

≥ 31 days

1. What was the approximate duration of your child’s overall period of hospitalization including their period of time in the PICU?

≤ 1 day

2 - 3 days

4 - 8 days

9 - 30 days

≥ 31 days

1. What was the reason/s for your child’s hospitalization in the pediatric intensive care unit (PICU)?

Pneumonia (Bacterial)

Pneumonia (Viral)

Asthma

Sepsis/Shock (Not Pneumonia)

Diabetes/Diabetic Ketoacidosis

Surgery or Surgical Complication

Heart Arrhythmia

Heart Valve Disorder

Congestive Heart Failure

Malignancy

Trauma/Injury

Seizures/Epilepsy

Liver Failure

Kidney Failure

Stroke

Metabolic/Endocrine (Not Diabetes)

Appendicitis

Neurologic Condition (Not Stroke)

Trauma/Injury

Attempted Suicide

Drug Overdose

Other, Specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_

Not Sure

1. Did your child receive any sedatives (drugs that cause your child to sleep/ become drowsy/undergo a medically induced coma) during hospitalization?

Yes

No

Not Sure

If yes, then drop down menu.

1. Which of the following sedatives or medications did your child receive? Please select all that apply.

Propofol

Lorazepam

Midazolam

Other, specify \_\_\_\_\_\_\_\_\_\_\_

Not Sure

**APPENDIX 2B**

**Questionnaire B:** **Children’s memories and recollection of experiences during life threatening illness reported by parents**

To better understand child’s memories and experiences during their time of unconsciousness in the Pediatric Intensive Care Unit an assessment was developed by a research team at New York University Langone Health and is being carried out at participating sites in the United States and United Kingdom. The following questions are directed towards parents of children who experienced memories after loss of consciousness and intend to gather further information on the perception of child’s memories and experiences.

*Instructions: Please answer the following questions:*

1. Did your child describe any perception of the following experiences during their time of life threatening illness:

|  |  |  |
| --- | --- | --- |
| Please select all that apply | **Yes** | **No** |
| 1. Watching himself/herself from above |  |  |
| 1. Traveling through a tunnel and/or towards a light |  |  |
| 1. Experiencing a feeling of peace or joy |  |  |
| 1. Seeing his/her relatives and/or peers |  |  |
| 1. Seeing objects in the form of light and/or human form |  |  |
| 1. Seeing pets and/or animals |  |  |
| 1. Recalling information during their time of unconsciousness |  |  |
| 1. Other |  |  |

1. Do you believe that these memories and/or experiences (Such as; peaceful feelings, a perception of a tunnel and/or a light, seeing relatives, a life review, and positive emotions, etc.) impacted your child’s quality of life after loss of consciousness, arising from their life threatening illness?

Yes

No

N/A

If yes selected it will result in a follow up question 3.

1. How would you describe this impact on your child’s quality of life?

Positive impact

Negative impact

Neutral

Other, specify \_\_\_\_\_\_\_\_\_\_\_

1. *Please explain below in as much detail as possible your child’s memories and/or experiences,* (such as; peaceful feelings, a perception of a tunnel and/or a light, seeing relatives, a life review, and positive emotions, etc.) your child reported during the time he/she was unconscious in the pediatric intensive care unit? *Please respond by writing below.*

**APPENDIX 3**

**Memories and/or recollection experiences reported by children who survived a critical illness.**

**Purpose:**

The purpose of this in-person or web-based/telephone interview is to gather information from children with parents who reported that their child experienced memories or awareness at the time of a life threatening illness resulting in loss of consciousness. These experiences have sometimes been referred to as a so-called Near Death Experience (NDE). Research coordinators will assist with the completion of four questionnaires from children whose parents completed appendix 2a and 2b of the study. The questionnaires have been modified to address those who are under the age of 18. For children under the age of 18 parental permission and assistance is required to speak with the child. In some instances, it may be necessary that the parent assists the child during the interview process. For children who may wish to depict (draw, sketch) their experiences and memories during unconsciousness an email address will be made available for parents to email pictures. Research coordinators have been trained to review the questionnaires with those who need assistance.

*Instructions: The following question concern memories and/or recollection experiences that are reported by children during unconsciousness.*

1. How did this interview take place (Webex)?

Video conference (Webex, Skype, Facetime)

Phone conversation

In person

Other (specify)

1. Did the child take part in the interview process and answering questions?

Yes, the child answered questions and participated in interview process.

Yes, the child was present but did not answer questions.

No, the child was not present and did not participate in interview process.

1. Was this interview recorded?

Audio

Video

No permission

1. What do you remember from the period of your unconsciousness during hospitalization?

*Feel free to respond to this question with a drawing or write in your own words.*

**APPENDIX 4**

**Revised Children’s Anxiety and Depression Scale - Children aged 8-17 years**

The Revised Child Anxiety and Depression Scale (RCADS) is a 47-item, youth self-report questionnaire with subscales including: separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, obsessive compulsive disorder, and low mood (major depressive disorder). It also yields a Total Anxiety Scale (sum of the 5 anxiety subscales) and a Total Internalizing Scale (sum of all 6 subscales).

*Instructions: After your time in the PICU how often have you been bothered by any of the following problems? Choose the best answer.*

Child/Young Person’s NAME: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Time: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 1 | I worry about things | Never | Sometimes | Often | Always |
| 2 | I feel very sad or empty | Never | Sometimes | Often | Always |
| 3 | When I have a problem, I get a funny feeling in my stomach | Never | Sometimes | Often | Always |
| 4 | I worry when I think I have done poorly at something | Never | Sometimes | Often | Always |
| 5 | I would feel afraid of being on my own at home | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 6 | Nothing is much fun anymore | Never | Sometimes | Often | Always |
| 7 | I feel scared when I have to take a test | Never | Sometimes | Often | Always |
| 8 | I feel worried when I think someone is angry with me | Never | Sometimes | Often | Always |
| 9 | I worry about being away from my parent | Never | Sometimes | Often | Always |
| 10 | I am bothered by bad or silly thoughts or pictures in my mind | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 11 | I have trouble sleeping | Never | Sometimes | Often | Always |
| 12 | I worry that I will do badly at my school work | Never | Sometimes | Often | Always |
| 13 | I worry that something awful will happen to someone in my family | Never | Sometimes | Often | Always |
| 14 | I suddenly feel as if I can’t breathe when there is no reason for this | Never | Sometimes | Often | Always |
| 15 | I have problems with my appetite | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 16 | I have to keep checking that I have done things right (like the switch is off, or the door is locked) | Never | Sometimes | Often | Always |
| 17 | I feel scared if I have to sleep on my own | Never | Sometimes | Often | Always |
| 18 | I have trouble going to school in the mornings because I feel nervous or afraid | Never | Sometimes | Often | Always |
| 19 | I have no energy for things | Never | Sometimes | Often | Always |
| 20 | I worry I might look foolish | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 21 | I am tired a lot | Never | Sometimes | Often | Always |
| 22 | I worry that bad things will happen to me | Never | Sometimes | Often | Always |
| 23 | I can’t seem to get bad or silly thoughts out of my head | Never | Sometimes | Often | Always |
| 24 | When I have a problem, my heart beats really fast | Never | Sometimes | Often | Always |
| 25 | I cannot think clearly | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 26 | I suddenly start to tremble or shake when there is no reason for this | Never | Sometimes | Often | Always |
| 27 | I worry that something bad will happen to me | Never | Sometimes | Often | Always |
| 28 | When I have a problem, I feel shaky | Never | Sometimes | Often | Always |
| 29 | I feel worthless | Never | Sometimes | Often | Always |
| 30 | I worry about making mistakes | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 31 | I have to think of special thoughts (like numbers or words) to stop bad things from happening | Never | Sometimes | Often | Always |
| 32 | I worry that what other people think of me | Never | Sometimes | Often | Always |
| 33 | I am afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds) | Never | Sometimes | Often | Always |
| 34 | All of a sudden I feel really scared for no reason at all | Never | Sometimes | Often | Always |
| 35 | I worry about what is going to happen | Never | Sometimes | Often | Always |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 36 | I suddenly become dizzy or faint when there is no reason for this | Never | Sometimes | Often | Always |
| 37 | I think about death | Never | Sometimes | Often | Always |
| 38 | I feel afraid if I have to talk in front of my class | Never | Sometimes | Often | Always |
| 39 | My heart suddenly starts to beat too quickly for no reason | Never | Sometimes | Often | Always |
| 40 | I feel like I don’t want to move | Never | Sometimes | Often | Always |
| 41 | I worry that I will suddenly get a scared feeling when there is nothing to be afraid of | Never | Sometimes | Often | Always |
| 42 | I have to do some things over and over again (like washing my hands, cleaning or putting things in certain order | Never | Sometimes | Often | Always |
| 43 | I feel afraid if I will make a fool of myself in front of people | Never | Sometimes | Often | Always |
| 44 | I have to do somethings in just the right way to stop bad things from happening | Never | Sometimes | Often | Always |
| 45 | I worry when I go to bed at night | Never | Sometimes | Often | Always |
| 46 | I would feel scared if I had to stay away from home overnight | Never | Sometimes | Often | Always |
| 47 | I feel restless | Never | Sometimes | Often | Always |

**Additionally, The Revised Child Anxiety and Depression Scale – Parent Version (RCADS-P) similarly assesses parent report of youth’s symptoms of anxiety and depression across the same six subscales.**

**Revised Parent Anxiety and Depression Scale** (children below 8 years old)

Child/Young Person’s NAME: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Relationship to child/young person: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

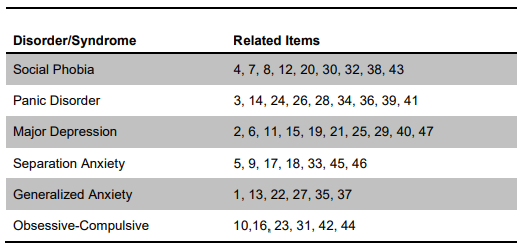
Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Time: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 1 | My child worries about things | Never | Sometimes | Often | Always |
| 2 | My child feels sad or empty | Never | Sometimes | Often | Always |
| 3 | When my child has a problem, he/she gets a funny feeling in his/her stomach | Never | Sometimes | Often | Always |
| 4 | My child worries when he/she thinks he/she has done poorly at something | Never | Sometimes | Often | Always |
| 5 | My child feels afraid of being alone at home | Never | Sometimes | Often | Always |
| 6 | Nothing is much fun for my child anymore | Never | Sometimes | Often | Always |
| 7 | My child feels scared when taking a test | Never | Sometimes | Often | Always |
| 8 | My child worries when he/she thinks someone is angry with him/her | Never | Sometimes | Often | Always |
| 9 | My child worries about being away from me | Never | Sometimes | Often | Always |
| 10 | My child is bothered by bad or silly thoughts or pictures in his/her mind | Never | Sometimes | Often | Always |
| 11 | My child has trouble sleeping | Never | Sometimes | Often | Always |
| 12 | My child worries about doing badly at school work | Never | Sometimes | Often | Always |
| 13 | My child worries that something awful will happen to someone in the family | Never | Sometimes | Often | Always |
| 14 | My child suddenly feels as if he/she can’t breathe when there is no reason for this | Never | Sometimes | Often | Always |
| 15 | My child has problems with his/her appetite | Never | Sometimes | Often | Always |
| 16 | My child has to keep checking that he/she has done things right (like the switch is off, or the door is locked) | Never | Sometimes | Often | Always |
| 17 | My child feels scared to sleep on his/her own | Never | Sometimes | Often | Always |
| 18 | My child has trouble going to school in the mornings because of feeling nervous or afraid | Never | Sometimes | Often | Always |
| 19 | My child has no energy for things | Never | Sometimes | Often | Always |
| 20 | My child worries about looking foolish | Never | Sometimes | Often | Always |
| 21 | My child is tired a lot | Never | Sometimes | Often | Always |
| 22 | My child worries that bad things will happen to him/her | Never | Sometimes | Often | Always |
| 23 | My child can’t seem to get bad or silly thoughts out of his/her head | Never | Sometimes | Often | Always |
| 24 | When my child has a problem, his/her heart beats really fast | Never | Sometimes | Often | Always |
| 25 | My child cannot think clearly | Never | Sometimes | Often | Always |
| 26 | My child suddenly starts to tremble or shake when there is no reason for this | Never | Sometimes | Often | Always |
| 27 | My child worries that something bad will happen to him/her | Never | Sometimes | Often | Always |
| 28 | When my child has a problem, he/she feels shaky | Never | Sometimes | Often | Always |
| 29 | My child feels worthless | Never | Sometimes | Often | Always |
| 30 | My child worries about making mistakes | Never | Sometimes | Often | Always |
| 31 | My child has to think of special thoughts (like numbers or words) to stop bad things from happening | Never | Sometimes | Often | Always |
| 32 | My child worries what other people think of him/her | Never | Sometimes | Often | Always |
| 33 | My child is afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds) | Never | Sometimes | Often | Always |
| 34 | All of a sudden my child will feel really scared for no reason at all | Never | Sometimes | Often | Always |
| 35 | My child worries about what is going to happen | Never | Sometimes | Often | Always |
| 36 | My child suddenly becomes dizzy or faint when there is no reason for this | Never | Sometimes | Often | Always |
| 37 | My child thinks about death | Never | Sometimes | Often | Always |
| 38 | My child feels afraid if he/she have to talk in front of the class | Never | Sometimes | Often | Always |
| 39 | My child’s heart suddenly starts to beat too quickly for no reason | Never | Sometimes | Often | Always |
| 40 | My child feels like he/she doesn’t want to move | Never | Sometimes | Often | Always |
| 41 | My child worries that he/she will suddenly get a scared feeling when there is nothing to be afraid of | Never | Sometimes | Often | Always |
| 42 | My child has to do some things over and over again (like washing hands, cleaning, or putting things in a certain order) | Never | Sometimes | Often | Always |
| 43 | My child feels afraid that he/she will make a fool of him/herself in front of people | Never | Sometimes | Often | Always |
| 44 | 4 My child has to do some things in just the right way to stop bad things from happening | Never | Sometimes | Often | Always |
| 45 | My child worries when in bed at night | Never | Sometimes | Often | Always |
| 46 | My child would feel scared if he/she had to stay away from home overnight | Never | Sometimes | Often | Always |
| 47 | My child feels restless | Never | Sometimes | Often | Always |

**Manual Scoring:**

To score the RCADS manually, each item is assigned a numerical value from 0-3, where 0 = Never, 1 = Sometimes, 2 = Often, and 3 = Always. For each subscale add the numerical values for each item together. The items that comprise each subscale are listed below. For example, for Generalized Anxiety you would add the numerical values for items 1, 13, 22, 27, 35, and 37. Thus, the highest score possible is 18, the lowest 0.



Missing data for raw scores can be handled by prorating the remaining items within a scale. It is recommended that scales with more than 2 missing items are not scored. Likewise, the total anxiety score can have up to 10 missing items, but only if each subscale has no more than 2 missing; and the total anxiety and depression score can have up to 12 missing items, but only if each subscale has no more than 2 missing items. To estimate the scale score, take the sum of the completed items within that scale and divide that by the number of items completed, then multiple by the total number of items in that scale, and then round the result. For example, if one item is missing from the separation anxiety scale (which has seven items), and the 6 completed items sum to 4, you would divide 4 by 6 (0.67), and then multiply by 7, which would yield 4.67, which then rounds to 5. Thus, you would count the score as a 5 not a 4 because of the prorating.