**Parent Survey**

1. Since you’ve been admitted to the PICU, did anyone from your child’s care team talk to you about how long your child might be in the PICU?

\_\_\_ Yes

\_\_\_ The providers said we will be in the PICU for < 3 days from PICU admission

\_\_\_ The providers said we will be in the PICU for 4-7 days from PICU admission

\_\_\_ The providers said we will be in the PICU for 1-2 weeks from PICU admission

\_\_\_ The providers said we will be in the PICU for > 2 weeks from PICU admission

\_\_\_ Yes, and nobody knows how long my child would be in the PICU.

\_\_\_ No, no one talked to me about how long my child might be in the PICU.

\_\_\_ I don’t know if this was discussed

1b. Who talked with you about the length of time you will be in the PICU?

Please mark all that apply:

\_\_ Physical therapist

\_\_ Respiratory therapist

\_\_ Bedside nurse

\_\_ PICU APN

\_\_ Resident Doctor

\_\_ PICU Fellow Doctor

\_\_ PICU Attending Doctor

\_\_ Social worker

\_\_ Case Manager

\_\_ Chaplain

\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Please describe. For example: My child’s oncologist, neurologist, neurosurgeon)

\_\_ I don't know

\_\_\_ Nobody

1c. Would you like more information about how long your child will be in the PICU?

\_\_\_Yes

\_\_\_ No

2a. Has anyone from your child’s care team talked to you about whether your child could have **new** problems with their body that they did not have before this admission?

Below are some examples of the kinds of problems that might have been discussed.

Please mark all that apply:

\_\_\_ A need for new medical technology (for example: Oxygen, a feeding tube, other respiratory support, dialysis):

\_\_\_ Need for oxygen at home

\_\_\_ Need for CPAP, BiPAP

\_\_\_ Need for tracheostomy with or without ventilator

\_\_\_ Need for a feeding tube (G-tube, J-tube)

\_\_\_ Need for Dialysis

\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Problems with everyday activities (for example: eating, walking, seeing etc.):

\_\_\_ Difficulties with eating or feeding

\_\_\_ Muscle weakness

\_\_\_ Problems with walking

\_\_\_ Problems with balance

\_\_\_ Problems with seeing

\_\_\_ Problems with hearing

\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Something not listed above

Please describe any other possible new physical problems discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, no one has discussed the possibility that my child might have new problems with their body.

\_\_\_ I don’t know if this was discussed

2b. Who talked with you about whether your child could have new problems with their body after this PICU admission?

Please mark all that apply:

\_\_ Physical therapist

\_\_ Respiratory therapist

\_\_ Bedside nurse

\_\_ APN

\_\_ Resident Doctor

\_\_ PICU Fellow Doctor

\_\_ PICU Attending Doctor

\_\_ Social worker

\_\_ Case Manager

\_\_ Chaplain

\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Please describe. For example: My child’s oncologist, neurologist, neurosurgeon)

\_\_ I don't know

\_\_ Nobody

2c. Would you like more information about whether your child could have new problems with their body after staying in the PICU?

\_\_\_Yes

\_\_\_ No

3a. Has anyone from your child’s care team talked to you about whether your child could have **new** problems with how their mind works after this PICU admission? Below are some examples of the kinds of problems that might have been discussed.

Please mark all that apply:

\_\_\_ Difficulties with thinking

\_\_\_ Difficulties with memory

\_\_\_ Difficulties with learning

\_\_\_ New or worsening seizures

\_\_\_ Something not listed above

Please describe any other possible problems with your child’s mind that were discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, no one discussed the possibility that my child might have new problems with how their mind works after this PICU admission

\_\_\_ I don’t know if this was discussed.

3b. Who talked to you about whether your child could have new problems with their mind after this PICU admission?

Please mark all that apply:

\_\_ Physical therapist

\_\_ Respiratory therapist

\_\_ Bedside nurse

\_\_ APN

\_\_ Resident Doctor

\_\_ PICU Fellow Doctor

\_\_ PICU Attending Doctor

\_\_ Social Worker

\_\_ Case Manager

\_\_ Chaplain

\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Please describe. For example: My child’s oncologist, neurologist, neurosurgeon)

\_\_ I don't know

\_\_ Nobody

3c. Would you like to more information about whether your child could have new problems with their mind after staying in the PICU?

\_\_\_Yes

\_\_\_ No

4a. Has anyone from your child’s care team talked to you about whether your child could have **new** challenging thoughts, feelings, or emotions after this PICU admission? Below are some examples of the kinds of changes that might have been discussed.

Please mark all that apply:

\_\_\_ Problems with anxiety

\_\_\_ Problems with depression

\_\_\_ Problems sleeping

\_\_\_ Problems with behavior

\_\_\_ Problems with recurrent or unwanted distressing memories about being in the PICU

\_\_\_ Something not listed above

Please describe any other possible problems related to challenging thoughts, feelings, or emotions that were discussed. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, no one discussed the possibility that my child might have new challenging thoughts, feelings, or emotions after this PICU admission.

\_\_\_ I don’t know

4b. Who talked to you about whether your child could have **new** challenging thoughts, feelings, or emotions after this PICU admission?

Please mark all that apply:

\_\_ Physical therapist

\_\_ Respiratory therapist

\_\_ Bedside nurse

\_\_ APN

\_\_ Resident Doctor

\_\_ PICU Fellow Doctor

\_\_ PICU Attending Doctor

\_\_ Social Worker

\_\_ Case Manager

\_\_ Chaplain

\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Please describe. For example: My child’s oncologist, neurologist, neurosurgeon)

\_\_ I don't know

\_\_ Nobody

4c. Would you like to more information about whether your child could have **new** problems with their thoughts, feelings or emotions after staying in the PICU?

\_\_\_Yes

\_\_\_ No

5a. Has anyone from your child’s care team talked to you about how your own emotional health might be impacted after your child’s stay in the PICU? Below are some examples of the kinds of changes that might have been discussed.

Please mark all that apply:

\_\_\_ Problems with anxiety

\_\_\_ Problems with depression

\_\_\_ Problems sleeping

\_\_\_ Problems with recurrent or unwanted distressing memories about being in the PICU

\_\_\_ Something not listed above

Please describe any other possible problems related to challenging thoughts, feelings, or emotions that were discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, no one discussed the possibility that my child’s stay in the PICU could impact my own emotional health.

\_\_\_ I don’t know if this was discussed

5b. Who talked to you about how your own emotional health might be impacted after your child’s stay in the PICU?

Please mark all that apply:

\_\_ Physical therapist

\_\_ Respiratory therapist

\_\_ Bedside nurse

\_\_ APN

\_\_ Resident Doctor

\_\_ PICU Fellow Doctor

\_\_ PICU Attending Doctor

\_\_ Social Worker

\_\_ Case Manager

\_\_ Chaplain

\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Please describe. For example: My child’s oncologist, neurologist, neurosurgeon)

\_\_ I don't know

\_\_ Nobody

5c. Would you like to have more information about how your own emotional health might be impacted after your child’s time in the PICU?

\_\_\_Yes

\_\_\_ No

6a. We have been asking about what would happen after your child leaves the PICU. Sometimes, despite our best efforts, children do not survive to leave the PICU. Have there been any discussions with the PICU team about the possibility that your child could not survive?

\_\_\_\_\_Yes

Please describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_ No

\_\_\_\_ I don’t know

6b. Who talked to you about the possibility that your child could not survive to leave the PICU?

Please mark all that apply:

\_\_ Physical therapist

\_\_ Respiratory therapist

\_\_ Bedside nurse

\_\_ APN

\_\_ Resident Doctor

\_\_ PICU Fellow Doctor

\_\_ PICU Attending Doctor

\_\_ Social Worker

\_\_ Case Manager

\_\_ Chaplain

\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Please describe. For example: My child’s oncologist, neurologist, neurosurgeon)

\_\_ I don't know

\_\_ Nobody

6c. Would you like to have more information about the likelihood of your child surviving to leave the PICU?

\_\_\_Yes

\_\_\_ No

**Physician Survey**

1. Since being admitted to the PICU, **did you or someone else** talk to the family about how long to expect **your patient** will be in the PICU? (Please note timeframe below represent estimated timeline that was discussed with the family)

\_\_\_ Yes

\_\_\_ < 3 days from PICU admission

\_\_\_ 4-7 days from PICU admission

\_\_\_ 1-2 weeks from PICU admission

\_\_\_ > 2 weeks from PICU admission

\_\_\_ Yes, but we have not been able to predict how long their child will be in the PICU

\_\_\_ No

\_\_\_ I don’t know if this was discussed

2. Has ***someone from the PICU team*** talked to the parents of your patient about whether **your patient** could have **new** **problems** **with their body** that they did not have before this PICU admission? Below are some examples of the kinds of problems that might have been discussed.

\_\_\_ Yes, ***I talked*** to this family about possible new physical problems.

Please mark all that apply:

\_\_\_ A need for new medical technology (for example: Oxygen, a feeding tube, other respiratory support, dialysis):

\_\_\_ Need for oxygen at home

\_\_\_ Need for CPAP, BiPAP

\_\_\_ Need for tracheostomy with or without ventilator

\_\_\_ Need for a Feeding tube (G-tube, J-tube)

\_\_\_ Need for Dialysis

\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Problems with everyday activities (for example: eating, walking, seeing etc.):

\_\_\_ Difficulties with eating or feeding

\_\_\_ Muscle weakness

\_\_\_ Problems with walking

\_\_\_ Problems with balance

\_\_\_ Problems with seeing

\_\_\_ Problems with hearing

\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_ Something not listed above

Please describe any other possible new physical problems discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Yes, ***someone else from the PICU team*** talked to this family about possible new physical problems.

Please mark all that apply:

\_\_\_ A need for new medical technology (for example: Oxygen, feeding tube):

\_\_\_ Need for oxygen at home

\_\_\_ Need for CPAP, BiPAP

\_\_\_ Need for tracheostomy with or without ventilator

\_\_\_ Need for a Feeding tube (G-tube, J-tube)

\_\_\_ Nee for Dialysis

\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Problems with everyday activities (for example: eating, walking, seeing etc.):

\_\_\_ Difficulties with eating/feeding

\_\_\_ Muscle weakness

\_\_\_ Problems with walking

\_\_\_ Problems with balance

\_\_\_ Problems with seeing

\_\_\_ Problems with hearing

\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_ Something not listed above

Please describe any other possible new physical problems discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, nobody from the PICU team talked to this family about possible new physical problems and this is why (please select all that apply):

\_\_\_ No new problems are expected

\_\_\_ The PICU team is unable to predict

\_\_\_ The PICU team is waiting for additional information

\_\_\_ The family is not ready to hear

\_\_\_ The family does not want to know

\_\_\_ Other (Please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I don’t know if this was discussed

3. Has ***someone from the PICU team*** talked to the parents of your patient about whether **your patient** could have **new problems with how their mind will work** after this PICU admission? Below are some examples of the kinds of problems that might have been discussed.

\_\_\_ Yes, ***I talked*** to the family about possible new neurologic problems

Please mark all that apply:

\_\_\_ Difficulties with thinking

\_\_\_ Difficulties with memory

\_\_\_ Difficulties with learning

\_\_\_ New or worsening seizures

\_\_\_ Something not listed above

Please describe any other possible problems with your patient’s mind that were discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Yes, ***someone else from the PICU team*** talked to this family about possible new neurologic problems

Please mark all that apply:

\_\_\_ Difficulties with thinking

\_\_\_ Difficulties with memory

\_\_\_ Difficulties with learning

\_\_\_ New or worsening seizures

\_\_\_ Something not listed above

Please describe any other possible new problems with your patient’s mind that were discussed\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, nobody from the PICU team talked to this family about possible new neurologic problems and this is why (please select all that apply):

\_\_\_ No new problems are expected

\_\_\_ The PICU team is unable to predict

\_\_\_ The PICU team is waiting for additional information

\_\_\_ The family is not ready to hear

\_\_\_ The family does not want to know

\_\_\_ Other (Please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I don’t know if this was discussed

4. Has ***someone from the PICU team*** talked to the parents of your patient about whether **your patient** could **new** **thoughts, feelings, or emotions** after staying in the ICU? Below are some examples of the kinds of changes that might have been discussed.

\_\_\_ Yes, ***I talked*** to the family about possible new emotional challenges

Please mark all that apply:

\_\_\_ Anxiety

\_\_\_ Depression

\_\_\_ Sleep disturbance

\_\_\_ Behavior changes

\_\_\_ Something not listed above

Please describe any other possible problems related to challenging thoughts, feelings, or emotions that were discussed\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Yes*,* ***someone else from the PICU team*** talked to the family about possible new emotional challenges

Please mark all that apply:

\_\_\_ Anxiety

\_\_\_ Depression

\_\_\_ Sleep disturbance

\_\_\_ Behavior changes

\_\_\_ Something not listed above

Please describe any other possible problems related to challenging thoughts, feelings, or emotions that were discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, nobody from the PICU team talked to this family about possible new emotional challenges and this is why (Please select all that apply):

\_\_\_ The PICU team cannot predict what new emotional challenges this patient may have

\_\_\_ There has not been time to discuss these new emotional challenges

\_\_\_ The patient already has emotional challenges

\_\_\_ The family has not asked the team about the potential for this patient’s new emotional challenges

\_\_\_ The PICU team did not feel it was indicated, and this is why \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Other (Please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I don’t know if this was discussed

5a. Has ***someone from the PICU team*** talked to the parents of your patient about whether **the parents’** emotional health might be impacted after having a child stay in the PICU? Below are some examples of the kinds of changes that might have been discussed.

\_\_\_ Yes, ***I talked*** to the family about possible new emotional challenges

Please mark all that apply:

\_\_\_ Problems with anxiety

\_\_\_ Problems with depression

\_\_\_ Problems sleeping

\_\_\_ Problems with recurrent or unwanted distressing memories about being in the PICU

\_\_\_ Something not listed above

Please describe any other possible problems related to challenging thoughts, feelings, or emotions that were discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Yes*,* ***someone else from the PICU team*** talked to the family about possible new emotional challenges

Please mark all that apply:

\_\_\_ Problems with anxiety

\_\_\_ Problems with depression

\_\_\_ Problems sleeping

\_\_\_ Problems with recurrent or unwanted distressing memories about being in the PICU

\_\_\_ Something not listed above

Please describe any other possible problems related to challenging thoughts, feelings, or emotions that were discussed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ No, nobody from the PICU team talked to this family about possible new emotional challenges and this is why (Please select all that apply):

\_\_\_ No new problems are expected

\_\_\_ The PICU team is unable to predict

\_\_\_ The PICU team is waiting for additional information

\_\_\_ The family is not ready to hear

\_\_\_ The family does not want to know

\_\_\_ Other (Please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I don’t know if this was discussed

6. Has ***anyone from the PICU team*** talked to the parents of your patient about the possibility that your patient will not survive?

\_\_\_ Yes, I ***talked*** to the family about this possibility

\_\_\_ Yes, ***someone else from the PICU team*** talked to the family about this possibility

\_\_\_ No, nobody from the PICU team talked to this family about this possibility and this is why (Please select all that apply):

\_\_\_ This patient will most certainly survive

\_\_\_ The PICU team is unable to predict

\_\_\_ The PICU team is waiting for additional information

\_\_\_ The family is not ready to hear

\_\_\_ The family does not want to know

\_\_\_ Other (Please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I don’t know