

Focus Group Questionnaire

1. How old was your child when they died?
☐ less than 1 year
☐ 1-4 years
☐ 5-9 years
☐ 10-14 years
☐ 15-19 years
☐ 20-24 years
☐ 25 years or older
2. What type of cancer did your child have? _____
3. When did your child die (month, year)? _____
4. Where did your child die?
☐ in the hospital on the general care floor
☐ in the intensive care unit
☐ at home
☐ other (please clarify _____)
5. Overall, how well do you think your child's death went?
☐ very well
☐ well
☐ unsure
☐ poorly
☐ very poorly
6. How long before your child's death do you think you knew that curing their disease was no longer an option? _____
7. Do you think your child knew that they were going to die? _____
 - a. If yes, how long before their death do you think your child knew that they were going to die? _____
 - b. Did they do something to make you think they knew at that time?

8. Many tough decisions are faced near the end of a child's life. When you think back to that time, do you feel that (please choose one):
☐ most decisions were made by me/my family
☐ most decisions were a shared decision between me/my family and the doctor
☐ most decisions were made by the doctor

9. Were you offered palliative care services?

____yes

____no

____unsure

10. Were you offered hospice services?

____yes

____no

____unsure

11. Was your child enrolled in hospice?

____yes

____no

____unsure

12. If you interacted with these services, how helpful were they in taking care of your child at the end of their life? Please choose one for each service.

	Did not interact with this service	Not helpful at all	A little helpful	Somewhat helpful	Very Helpful
Child Life					
Pain Team					
Palliative Care					
Psychiatry/Psychology					
Social Work					
Spiritual Care					

13. How well was your child's pain controlled at the end of life?

____very well

____well

____neutral

____poorly

____very poorly

____my child did not need any pain control

14. How well was your child's nausea controlled at the end of life?

- ☐ very well
- ☐ well
- ☐ neutral
- ☐ poorly
- ☐ very poorly
- ☐ my child did not need any nausea control

15. How well was your child's difficulty with breathing controlled at the end of life?

- ☐ very well
- ☐ well
- ☐ neutral
- ☐ poorly
- ☐ very poorly
- ☐ my child did not need any help due to difficulty breathing

16. What is your gender? _____

17. What is your age? _____

18. What is your relationship to the child who died? _____