Supplementary Online Content


**eAppendix.** Methods

This supplementary material has been provided by the authors to give readers additional information about their work.
Reasons Why Parents Agree or Do Not Agree to Have Their Children Take Part in Research

Recently, you were asked to allow your child to be in a research study. We are interested in learning how parents think about having their children participate in research.

Part I. Please answer all questions

1. Did you decide to let your child be in the research study?  
   - Yes 1  
   - No 0

2. Has your child ever been in a research study before?  
   - Yes 1  
   - No 0
   
   If yes, how satisfied were you with that other experience?  
   - Satisfied 1  
   - Neutral 2  
   - Not satisfied 3

3. Have you ever been in a research study?  
   - Yes 1  
   - No 0
   
   If yes, how satisfied were you with that experience?  
   - Satisfied 1  
   - Neutral 2  
   - Not satisfied 3

4. Do you have family or friends who participated in research studies?  
   - Yes 1  
   - No 0

Part II.

5. Did you receive the copy of the consent form?  
   - Yes 1  
   - No 0 (Please skip to Part III)

6. Did someone go over the consent form with you?  
   - Yes 1  
   - No 0

7. I felt the consent form was easy to read.  
   - Strongly disagree 1  
   - Disagree 2  
   - Neither agree nor disagree 3  
   - Agree 4  
   - Strongly agree 5

8. I had enough time to read the consent form.  
   - Strongly disagree 1  
   - Disagree 2  
   - Neither agree nor disagree 3  
   - Agree 4  
   - Strongly agree 5

9. I understood the consent form.  
   - Strongly disagree 1  
   - Disagree 2  
   - Neither agree nor disagree 3  
   - Agree 4  
   - Strongly agree 5

10. Was the information in the consent form the same as the information discussed with you?  
   - The same 1  
   - Mostly the same 2  
   - Different 3  
   - Don’t know 4  
   - Not applicable 5

11. Was the amount of information in the consent form:  
   - Too little 1  
   - Just right 2  
   - Too much 3

Part III. This section asks you about things that may have influenced your decision about your child’s participation in the study.

<table>
<thead>
<tr>
<th>Circle the number that best describes your answer.</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. I had enough time to decide.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I had enough privacy to decide.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I felt pressured to make a decision.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. The person who presented the study made me feel comfortable.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I know the risks of the study.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. The person who presented the study did a good job explaining the study.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I felt rushed into making a decision.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. The person who presented the study was friendly.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I have a positive attitude toward medical research.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Circle the number that best describes your answer.**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I felt like the decision to have my child take part in the study was up to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. Medical researchers are honest with the people they want to be in their studies.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. The person who discussed the study was very professional.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. I trust the study doctors to put my child’s safety before the needs of their study.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. My decision was influenced by my desire to help other children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. Doctors do not really know which of the two treatments is better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. My child has an equal chance of getting either treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28. I will not know which treatment my child is getting.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29. The researcher will know which treatment my child is getting.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. I can take my child out of the study at any time that I choose.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>31. I think allowing my child to be in the study will provide the best medical care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**PART IV. Please circle a number from 0 to 10 to answer each question below.**

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. How much risk do you think the study involves?</td>
<td>0-10</td>
</tr>
<tr>
<td>33. How much benefit do you think your child would receive by being in the study?</td>
<td>0-10</td>
</tr>
<tr>
<td>34. How much benefit do you think other children would receive by your child being in the study?</td>
<td>0-10</td>
</tr>
<tr>
<td>35. How important do you think the study is?</td>
<td>0-10</td>
</tr>
<tr>
<td>36. How much anxiety did you have regarding your child’s participation in the study?</td>
<td>0-10</td>
</tr>
</tbody>
</table>

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37. How hard was it to make a decision about having your child in the study?

0 1 2 3 4 5 6 7 8 9 10
Not hard to make          Extremely hard to make

38. I am ok with not knowing which treatment my child is receiving.

0 1 2 3 4 5 6 7 8 9 10
Strongly Agree          Strongly Disagree

39. I was worried that the study might get in the way of my child’s medical care.

0 1 2 3 4 5 6 7 8 9 10
Strongly Agree          Strongly Disagree

Part V. Please answer all questions

40. Please describe the person who gave you information about the study.

 a. Position:
   1 □ Your doctor
   2 □ Another doctor
   3 □ Research Nurse
   4 □ Other person (explain) ________________
   5 □ Don’t know

 b. Gender:
   1 □ Male  2 □ Female

41. Was the amount of information discussed with you about the study:
   □ Too little 1  □ Just right 2  □ Too much 3

42. Did the person who discussed the study listen to your concerns carefully?
   □ Yes 1  □ No 0  □ Not applicable 2

43. Did the person who discussed the study answer all of your questions?
   □ Yes 1  □ No 0  □ Not applicable 2

44. Did you talk with anyone else before making your decision about being in the study?
   □ Yes 1  □ No 0
   a. If yes, with whom (check all that apply)?
      □ Spouse
      □ Your child’s doctor
      □ Friend
      □ Another health care professional
      □ Family member ________________
b. How much did this person help you make your decision?

☐ A lot 1  ☐ A little 2  ☐ Not at all 3

45. Did your child want to be in the study?

☐ Yes 1  ☐ No 0  ☐ Too young 2

46. Did your child’s decision influence your own decision?

☐ Yes 1  ☐ No 0  ☐ Not applicable 2

47. When making decisions regarding your child’s medical care do you:

a) ☐ make most of the decisions yourself (or with family) 1

b) ☐ share the decision making equally with your doctor 2

  c) ☐ let the doctor make most of the decisions 3

48. If you agreed to let your child be in this study, what was your main reason for saying yes?

__________________________________________________________________________________________________

__________________________________________________________________________________________________

__________________________________________________________________________________________

49. If you did not agree to let your child participate in this study, what was your main reason for saying no?

__________________________________________________________________________________________________

__________________________________________________________________________________________________

__________________________________________________________________________________________

50. In the future, what could we do to help you make a decision about your child being in a research study?

__________________________________________________________________________________________________

__________________________________________________________________________________________________

__________________________________________________________________________________________________

__________________________________________________________________________________________________

PART VI. Please check the answer to the question.

51. What is your relationship to the child?

☐ Mother 1  ☐ Father 2
52. What is your child’s racial identity (check all that apply)?
- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Prefer not to answer

What is your child’s ethnicity?
- Hispanic or Latino 1
- Not Hispanic or Latino 0

53. What is your highest level of education?
- Less than high school 1
- High school graduate or GED 2
- Some college/technical school 3
- College graduate or more 4

54. Is English your first language?
- Yes 1
- No 0

If no, was language a problem for you to understand the study?
- Yes 1
- No 0

55. What is your primary medical insurance?
- Public (medical assistance) 1
- Private 2
- Do not have insurance 3

56. What is your child’s sex?
- Male 1
- Female 2

57. What is your child’s age? ______________

58. In general, my child seems less healthy than other children.
- Yes 1
- No 0

59. What is your age? ______________

PART VII.

60. Would you consider having your child participate in a future research study?
- Yes 1
- No 0
- Not sure 2

61. If you did not want your child to be in the recent study, which of the following things would make you agree to have your child be in a future study.

62. Please check all items that you would consider.

1. You could understand the consent form.
2. You had more time to make a decision.
3. There were no or fewer risks involved.
4. You could consult with your family or doctor.
5. You felt the study provided benefit to your child.
6. The researcher put you at ease.

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<table>
<thead>
<tr>
<th></th>
<th>You were approached in a more private setting.</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>You felt the study provided benefit to others.</td>
</tr>
<tr>
<td>6</td>
<td>Fewer visits and less time commitment.</td>
</tr>
<tr>
<td>7</td>
<td>You could understand the study.</td>
</tr>
<tr>
<td>8</td>
<td>The study provided child care services.</td>
</tr>
<tr>
<td>16</td>
<td>Other (<em>Please explain</em>)</td>
</tr>
<tr>
<td>12</td>
<td>The study did not involve a chance of your child getting a placebo or study drug.</td>
</tr>
<tr>
<td>13</td>
<td>The study provided reimbursement for transportation costs.</td>
</tr>
<tr>
<td>14</td>
<td>Study medication provided.</td>
</tr>
<tr>
<td>15</td>
<td>You felt no pressure to consent.</td>
</tr>
</tbody>
</table>

63. Please go back and **CIRCLE THE MOST IMPORTANT** factor listed above in making your decision. Thank you very much for your help with this survey.