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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| **Study Communications and Activities** |  |  |  |
| 1. Before the study started, I felt the study team gave me enough information about the study. |  | 1. Before the study started, I felt the study team gave me enough information about the study. |  |
| Strongly Agree | 98 (54.7%) | Strongly Agree | 138 (75.4%) |
| Agree | 69 (38.5%) | Agree | 39 (21.3%) |
| Neither Disagree Nor Agree | 7 (3.9%) | Neither Disagree Nor Agree | 1 (0.5%) |
| Disagree | 2 (1.1%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 2 (1.1%) | Strongly Disagree | 4 (2.2%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 2. I felt that if I did not agree to be in the study, the study team would be disappointed in me. |  | 2. I felt that if I did not agree to be in the study, the study team would be disappointed in me. |  |
| Strongly Agree | 3 (1.7%) | Strongly Agree | 7 (3.8%) |
| Agree | 7 (3.9%) | Agree | 6 (3.3%) |
| Neither Disagree Nor Agree | 31 (17.3%) | Neither Disagree Nor Agree | 11 (6.0%) |
| Disagree | 55 (30.7%) | Disagree | 52 (28.4%) |
| Strongly Disagree | 82 (45.8%) | Strongly Disagree | 107 (58.5%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 3. During the study, I knew who to talk to if I had a question about the study. |  | 3. During the study, I knew who to call if I had a question about the study. |  |
| Strongly Agree | 91 (50.8%) | Strongly Agree | 147 (80.3%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Agree | 75 (41.9%) | Agree | 30 (16.4%) |
| Neither Disagree Nor Agree | 6 (3.4%) | Neither Disagree Nor Agree | 1 (0.5%) |
| Disagree | 3 (1.7%) | Disagree | 2 (1.1%) |
| Strongly Disagree | 3 (1.7%) | Strongly Disagree | 2 (1.1%) |
| Missing | 1 (0.6%) | Missing | 1 (0.5%) |
| 4. Being in the study was inconvenient for me/my family. |  | 4. Being in the study was inconvenient for me/my family. |  |
| Strongly Agree | 6 (3.4%) | Strongly Agree | 5 (2.7%) |
| Agree | 9 (5.0%) | Agree | 15 (8.2%) |
| Neither Disagree Nor Agree | 24 (13.4%) | Neither Disagree Nor Agree | 34 (18.6%) |
| Disagree | 62 (34.6%) | Disagree | 61 (33.3%) |
| Strongly Disagree | 77 (43.0%) | Strongly Disagree | 67 (36.6%) |
| Missing | 1 (0.6%) | Missing | 1 (0.5%) |
| 5. After the study was explained, I was given enough time to make a decision about participating. |  | 5. After the study was explained, I was given enough time to make a decision about participating. |  |
| Strongly Agree | 96 (53.6%) | Strongly Agree | 134 (73.2%) |
| Agree | 76 (42.5%) | Agree | 44 (24.0%) |
| Neither Disagree Nor Agree | 4 (2.2%) | Neither Disagree Nor Agree | 2 (1.1%) |
| Disagree | 1 (0.6%) | Disagree | 2 (1.1%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 1 (0.5%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 6. The risks of joining the study were explained to me. |  | 6. The risks of joining the study were explained to me. |  |
| Strongly Agree | 87 (48.6%) | Strongly Agree | 134 (73.2%) |
| Agree | 81 (45.3%) | Agree | 48 (26.2%) |
| Neither Disagree Nor Agree | 7 (3.9%) | Neither Disagree Nor Agree | 0 (0.0%) |
| Disagree | 3 (1.7%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 1 (0.5%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 7. The benefits of joining the study were explained to me. |  | 7. The benefits of joining the study were explained to me. |  |
| Strongly Agree | 97 (54.2%) | Strongly Agree | 134 (73.2%) |
| Agree | 77 (43.0%) | Agree | 48 (26.2%) |
| Neither Disagree Nor Agree | 4 (2.2%) | Neither Disagree Nor Agree | 0 (0.0%) |
| Disagree | 0 (0.0%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 1 (0.5%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 8. The information in the consent form was the same as the information told to me. |  | 8. The information in the consent form was the same as the information discussed with me. |  |
| Strongly Agree | 88 (49.2%) | Strongly Agree | 133 (72.7%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Agree | 74 (41.3%) | Agree | 47 (25.7%) |
| Neither Disagree Nor Agree | 15 (8.4%) | Neither Disagree Nor Agree | 2 (1.1%) |
| Disagree | 0 (0.0%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 1 (0.5%) |
| Missing | 2 (1.1%) | Missing | 0 (0.0%) |
| 9. I knew I could leave the study at any time. |  | 9. I knew I could leave the study at any time. |  |
| Strongly Agree | 82 (45.8%) | Strongly Agree | 141 (77.0%) |
| Agree | 59 (33.0%) | Agree | 35 (19.1%) |
| Neither Disagree Nor Agree | 17 (9.5%) | Neither Disagree Nor Agree | 3 (1.6%) |
| Disagree | 16 (8.9%) | Disagree | 3 (1.6%) |
| Strongly Disagree | 3 (1.7%) | Strongly Disagree | 1 (0.5%) |
| Missing | 2 (1.1%) | Missing | 0 (0.0%) |
| 10. Looking back, I feel I had a good understanding of the study. |  | 10. Looking back, I feel I had a good understanding of the study. |  |
| Strongly Agree | 103 (57.5%) | Strongly Agree | 141 (77.0%) |
| Agree | 68 (38.0%) | Agree | 39 (21.3%) |
| Neither Disagree Nor Agree | 5 (2.8%) | Neither Disagree Nor Agree | 1 (0.5%) |
| Disagree | 2 (1.1%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 1 (0.5%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| **Study Team** |  |  |  |
| 11. The study team listened to my concerns about the study. |  | 11. The study team listened to my concerns about the study. |  |
| Strongly Agree | 77 (43.0%) | Strongly Agree | 132 (72.1%) |
| Agree | 82 (45.8%) | Agree | 48 (26.2%) |
| Neither Disagree Nor Agree | 18 (10.1%) | Neither Disagree Nor Agree | 3 (1.6%) |
| Disagree | 1 (0.6%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 12. The study team was more interested in the needs of their study than me. |  | 12. The study team was more interested in the needs of their study than in my child. |  |
| Strongly Agree | 3 (1.7%) | Strongly Agree | 4 (2.2%) |
| Agree | 5 (2.8%) | Agree | 3 (1.6%) |
| Neither Disagree Nor Agree | 19 (10.6%) | Neither Disagree Nor Agree | 9 (4.9%) |
| Disagree | 62 (34.6%) | Disagree | 43 (23.5%) |
| Strongly Disagree | 89 (49.7%) | Strongly Disagree | 124 (67.8%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 13. The study team did a good job of explaining the details of the study. |  | 13. The study team did a good job of explaining the details of the study. |  |
| Strongly Agree | 110 (61.5%) | Strongly Agree | 138 (75.4%) |

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| **Participant (** **Adolescent ) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Agree | 64 (35.8%) | Agree | 43 (23.5%) |
| Neither Disagree Nor Agree | 2 (1.1%) | Neither Disagree Nor Agree | 0 (0.0%) |
| Disagree | 3 (1.7%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 1 (0.5%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 14. The study team was available throughout the study to answer my questions. |  | 14. The study team was available throughout the study to answer my questions. |  |
| Strongly Agree | 107 (59.8%) | Strongly Agree | 137 (74.9%) |
| Agree | 64 (35.8%) | Agree | 42 (23.0%) |
| Neither Disagree Nor Agree | 7 (3.9%) | Neither Disagree Nor Agree | 3 (1.6%) |
| Disagree | 1 (0.6%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 15. The study team helped to make my research experience better. |  | 15. The study team helped to make my research experience better. |  |
| Strongly Agree | 95 (53.1%) | Strongly Agree | 138 (75.4%) |
| Agree | 74 (41.3%) | Agree | 40 (21.9%) |
| Neither Disagree Nor Agree | 10 (5.6%) | Neither Disagree Nor Agree | 4 (2.2%) |
| Disagree | 0 (0.0%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 16. The person who presented the study made me feel comfortable. |  | 16. The person who presented the study made me feel comfortable. |  |
| Strongly Agree | 108 (60.3%) | Strongly Agree | 149 (81.4%) |
| Agree | 64 (35.8%) | Agree | 32 (17.5%) |
| Neither Disagree Nor Agree | 3 (1.7%) | Neither Disagree Nor Agree | 2 (1.1%) |
| Disagree | 3 (1.7%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 17. I feel the study team was organized. |  | 17. I feel the study team was organized. |  |
| Strongly Agree | 105 (58.7%) | Strongly Agree | 145 (79.2%) |
| Agree | 65 (36.3%) | Agree | 34 (18.6%) |
| Neither Disagree Nor Agree | 8 (4.5%) | Neither Disagree Nor Agree | 2 (1.1%) |
| Disagree | 0 (0.0%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 2 (1.1%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 18. If/when I had a question, I felt comfortable talking to the study team. |  | 18. If/when I had a question, I felt comfortable contacting the study team. |  |
| Strongly Agree | 104 (58.1%) | Strongly Agree | 148 (80.9%) |
| Agree | 62 (34.6%) | Agree | 31 (16.9%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Neither Disagree Nor Agree | 10 (5.6%) | Neither Disagree Nor Agree | 4 (2.2%) |
| Disagree | 2 (1.1%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 0 (0.0%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| **Medical Care** |  |  |  |
| 19. I feel the study delayed my medical care. |  | 19. I feel the study delayed my child’s medical care. |  |
| Strongly Agree | 2 (1.1%) | Strongly Agree | 3 (1.6%) |
| Agree | 4 (2.2%) | Agree | 1 (0.5%) |
| Neither Disagree Nor Agree | 10 (5.6%) | Neither Disagree Nor Agree | 4 (2.2%) |
| Disagree | 65 (36.3%) | Disagree | 39 (21.3%) |
| Strongly Disagree | 90 (50.3%) | Strongly Disagree | 133 (72.7%) |
| N/A | 8 (4.5%) | N/A | 3 (1.6%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 20. I learned more about my condition by being in the study. |  | 20. I learned more about my child’s condition by being in the study. |  |
| Strongly Agree | 33 (18.4%) | Strongly Agree | 29 (15.8%) |
| Agree | 57 (31.8%) | Agree | 45 (24.6%) |
| Neither Disagree Nor Agree | 58 (32.4%) | Neither Disagree Nor Agree | 79 (43.2%) |
| Disagree | 21 (11.7%) | Disagree | 18 (9.8%) |
| Strongly Disagree | 4 (2.2%) | Strongly Disagree | 3 (1.6%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| N/A | 6 (3.4%) | N/A | 9 (4.9%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 21. I understood which procedure(s) were for research and which were standard for my condition. |  | 21. I understood which procedure(s) were for research and which were standard for my child’s condition. |  |
| Strongly Agree | 56 (31.3%) | Strongly Agree | 86 (47.0%) |
| Agree | 80 (44.7%) | Agree | 75 (41.0%) |
| Neither Disagree Nor Agree | 26 (14.5%) | Neither Disagree Nor Agree | 13 (7.1%) |
| Disagree | 6 (3.4%) | Disagree | 2 (1.1%) |
| Strongly Disagree | 2 (1.1%) | Strongly Disagree | 1 (0.5%) |
| N/A | 9 (5.0%) | N/A | 6 (3.3%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| 22. I feel being in the study gave me the best medical care. |  | 22. I feel being in the study provided the best medical care for my child. |  |
| Strongly Agree | 52 (29.1%) | Strongly Agree | 71 (38.8%) |
| Agree | 73 (40.8%) | Agree | 60 (32.8%) |
| Neither Disagree Nor Agree | 44 (24.6%) | Neither Disagree Nor Agree | 42 (23.0%) |
| Disagree | 3 (1.7%) | Disagree | 3 (1.6%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 1 (0.5%) |
| N/A | 6 (3.4%) | N/A | 6 (3.3%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| 23. I feel the study team and the medical team worked well together. |  | 23. I feel the study team and the medical team worked well together. |  |
| Strongly Agree | 91 (50.8%) | Strongly Agree | 117 (63.9%) |
| Agree | 79 (44.1%) | Agree | 52 (28.4%) |
| Neither Disagree Nor Agree | 6 (3.4%) | Neither Disagree Nor Agree | 7 (3.8%) |
| Disagree | 0 (0.0%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 2 (1.1%) |
| N/A | 3 (1.7%) | N/A | 4 (2.2%) |
| Missing | 0 (0.0%) | Missing | 0 (0.0%) |
| **Study Expectations** |  |  |  |
| 24. I am grateful (glad/thankful) I could join this study. |  | 24. I am grateful I had the opportunity to participate in this study. |  |
| Strongly Agree | 89 (49.7%) | Strongly Agree | 100 (54.6%) |
| Agree | 76 (42.5%) | Agree | 77 (42.1%) |
| Neither Disagree Nor Agree | 11 (6.1%) | Neither Disagree Nor Agree | 6 (3.3%) |
| Disagree | 2 (1.1%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 25. I feel I was helping future patients by being in this study. |  | 25. I feel I was helping future families by being in this study. |  |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Strongly Agree | 93 (52.0%) | Strongly Agree | 128 (69.9%) |
| Agree | 81 (45.3%) | Agree | 55 (30.1%) |
| Neither Disagree Nor Agree | 3 (1.7%) | Neither Disagree Nor Agree | 0 (0.0%) |
| Disagree | 0 (0.0%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 26. I would consider being in another study. |  | 26. I would consider having my child participate in another study. |  |
| Strongly Agree | 88 (49.2%) | Strongly Agree | 114 (62.3%) |
| Agree | 63 (35.2%) | Agree | 58 (31.7%) |
| Neither Disagree Nor Agree | 22 (12.3%) | Neither Disagree Nor Agree | 10 (5.5%) |
| Disagree | 2 (1.1%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 3 (1.7%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 27. I feel that I had a good understanding of what being in this research study involved. |  | 27. I feel that I had a good understanding of what being in this research study involved. |  |
| Strongly Agree | 87 (48.6%) | Strongly Agree | 121 (66.1%) |
| Agree | 83 (46.4%) | Agree | 61 (33.3%) |
| Neither Disagree Nor Agree | 5 (2.8%) | Neither Disagree Nor Agree | 0 (0.0%) |
| Disagree | 3 (1.7%) | Disagree | 1 (0.5%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 28. Being in the study made it hard to spend time with my friends and family. |  | 28. Being in the study made it difficult to balance time with my family. |  |
| Strongly Agree | 1 (0.6%) | Strongly Agree | 5 (2.7%) |
| Agree | 5 (2.8%) | Agree | 5 (2.7%) |
| Neither Disagree Nor Agree | 9 (5.0%) | Neither Disagree Nor Agree | 21 (11.5%) |
| Disagree | 63 (35.2%) | Disagree | 63 (34.4%) |
| Strongly Disagree | 100 (55.9%) | Strongly Disagree | 89 (48.6%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 29. The study team made me feel like my opinions were important during the study. |  | 29. The study team made me feel like my opinions were important during the study process. |  |
| Strongly Agree | 71 (39.7%) | Strongly Agree | 94 (51.4%) |
| Agree | 85 (47.5%) | Agree | 77 (42.1%) |
| Neither Disagree Nor Agree | 16 (8.9%) | Neither Disagree Nor Agree | 11 (6.0%) |
| Disagree | 2 (1.1%) | Disagree | 1 (0.5%) |
| Strongly Disagree | 3 (1.7%) | Strongly Disagree | 0 (0.0%) |
| Missing | 2 (1.1%) | Missing | 0 (0.0%) |
| 30. I have a positive attitude toward medical research. |  | 30. I have a positive attitude toward medical research. |  |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| Strongly Agree | 89 (49.7%) | Strongly Agree | 121 (66.1%) |
| Agree | 74 (41.3%) | Agree | 59 (32.2%) |
| Neither Disagree Nor Agree | 13 (7.3%) | Neither Disagree Nor Agree | 3 (1.6%) |
| Disagree | 1 (0.6%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 31. My expectations of the study were met. |  | 31. My expectations of the study were met. |  |
| Strongly Agree | 78 (43.6%) | Strongly Agree | 112 (61.2%) |
| Agree | 78 (43.6%) | Agree | 62 (33.9%) |
| Neither Disagree Nor Agree | 19 (10.6%) | Neither Disagree Nor Agree | 9 (4.9%) |
| Disagree | 3 (1.7%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 0 (0.0%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| 32. I feel it is important to be in a research study. |  | 32. I feel it is important to be in a research study. |  |
| Strongly Agree | 74 (41.3%) | Strongly Agree | 106 (57.9%) |
| Agree | 74 (41.3%) | Agree | 60 (32.8%) |
| Neither Disagree Nor Agree | 25 (14.0%) | Neither Disagree Nor Agree | 17 (9.3%) |
| Disagree | 3 (1.7%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 2 (1.1%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| 33. I would recommend being in a research study to others. |  | 33. I would recommend participation in a research study to others. |  |
| Strongly Agree | 76 (42.5%) | Strongly Agree | 117 (63.9%) |
| Agree | 74 (41.3%) | Agree | 53 (29.0%) |
| Neither Disagree Nor Agree | 25 (14.0%) | Neither Disagree Nor Agree | 13 (7.1%) |
| Disagree | 2 (1.1%) | Disagree | 0 (0.0%) |
| Strongly Disagree | 1 (0.6%) | Strongly Disagree | 0 (0.0%) |
| Missing | 1 (0.6%) | Missing | 0 (0.0%) |
| **After Survey Questions** |  |  |  |
| 34. Have you or someone in your immediate family (mother, father, sister, brother, other child) ever been in a research study? |  | 37. Have you or someone in your immediate family (mother, father, sister, brother, other child) ever been in a research study? |  |
| No | 81 (45.3%) | No | 119 (65.0%) |
| Yes | 41 (22.9%) | Yes | 47 (25.7%) |
| Don't Know | 54 (30.2%) | Don't Know | 16 (8.7%) |
| Missing | 3 (1.7%) | Missing | 1 (0.5%) |
| 35. Have you or someone in your immediate family (mother, father, sister, brother, Other child) ever worked on aresearch study? |  | 38. Have you or someone in your immediate family (mother, father, sister, brother, Other child) ever worked on aresearch study? |  |

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| **Participant (Adolescent) Survey Results (n = 179)** | **Parent Survey Results (n = 183\*)** |
| No | 105 (58.7%) | No | 155 (84.7%) |
| Yes | 17 (9.5%) | Yes | 18 (9.8%) |
| Don't Know | 54 (30.2%) | Don't Know | 8 (4.4%) |
| Missing | 3 (1.7%) | Missing | 2 (1.1%) |
| \* 183 total parent surveys collected, of which 174 came from at least one parent, and 9 had two-parent/guardian responses |