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This is the version of the survey fielded in our study. Based on feedback our study team received after the study was completed (both during our NQF submission and various presentations to academic and clinical audiences), the FECC measures and survey questions were refined. For example, we added the existence of a CC outside the main provider's office to the measure specification and thus, to the survey. The revised version of the survey along with measure specifications can be found at <http://www.seattlechildrens.org/research/child-health-behavior-and-development/mangione-smith-lab/measurement-tools/>

## YOUR EXPERIENCES WITH YOUR CHILD'S HEALTH CARE



*Answer the questions in this survey for the child named in the letter that came with this survey.*

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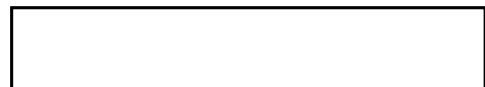
**Your Privacy is Protected.** All information that would let someone identify you or your family will be kept private. RAND will not share your personal information with anyone outside the study team, except as required by law.

**Your responses to this survey will be kept confidential.** Your individual answers will never be seen by your child's care providers or anyone else involved with your child's health care. You may notice a number on the cover of the survey. This number is used only to let us know if you returned your survey so we don't have to send you reminders.

**Your Participation is Voluntary.** Your decision to participate or not to participate will not affect your family's health care benefits in any way.

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**If you want to know more about this study,** please call RAND at 1-866-690-1650. All calls to that number are free.

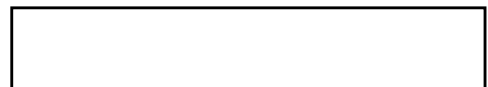




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## Survey Instructions

- ◆ Use a dark colored pen to fill out the survey.
- ◆ Please print your answers to write in questions.
- ◆ Place a X directly inside the square indicating a response, like in the sample below.
  - Yes
  - No
- ◆ To indicate an answer selected in error clearly draw a line through the square and select another square with an X like this:
  - Yes
  - ~~No~~
- ◆ You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:
  - Yes → **If Yes, go to #1 on Page 1**
  - No





### Your Child's Main Provider

1. Your child's **main provider** is the doctor, physician assistant, nurse or other health care provider who knows the most about your child's health, and who is in charge of your child's care overall. Which of the providers named below is your child's main provider?  
(If none of the providers listed below are your child's main provider, please write in the name of that provider at the bottom of the list.)

- None of these are my child's main provider, my child's main provider is written below.



*Please print provider's name:*

*Please print this provider's address:*

The questions in this survey will refer to the provider you marked in Question 1 as "the main provider." Please think of that person as you answer the questions.

### Care from Your Child's Main Provider in the Last 12 Months

2. In the last 12 months, did you phone the main provider's office to get an appointment for your child for an illness, injury or condition that **needed care right away**?
- Yes
- No → **If No, go to #5**
3. In the last 12 months, when you phoned the main provider's office to get an appointment for care your child **needed right away**, how often did you get an appointment as soon as your child needed?
- Never    Sometimes    Usually    Always



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4. In the last 12 months, did your child visit an urgent care center or an emergency room because you could not get an appointment at the main provider's office when you needed one?  
 Yes  
 No
  
5. In the last 12 months, did you make any appointments for a **check-up or routine care** for your child with the main provider?  
 Yes  
 No → **If No, go to #7**
  
6. In the last 12 months, when you made an appointment for a **check-up or routine care** for your child with the main provider, how often did you get an appointment as soon as your child needed?  
 Never  
 Sometimes  
 Usually  
 Always
  
7. In the last 12 months, did you phone the main provider's office with a medical question about your child during regular office hours?  
 Yes  
 No → **If No, go to #9**
  
8. In the last 12 months, when you phoned the main provider's office during regular office hours, how often did you get an answer to your medical question that same day?  
 Never  
 Sometimes  
 Usually  
 Always
  
9. Wait time includes time spent in the waiting room and exam room. In the last 12 months, how often did your child see the main provider **within 15 minutes** of his or her appointment time?  
 Never  
 Sometimes  
 Usually  
 Always





### Getting Help to Manage Your Child's Care

The next questions are about the people in the main provider's office who may help you manage care, treatment and services for your child.

10. In the last 12 months, did your child visit more than one doctor's office or use more than one kind of health care service?

Yes

No → **If No, go to #21**

11. Did anyone in the main provider's office help you to manage your child's care or treatment from these different doctors or care providers?

Yes

No → **If No, go to #21**

12. Who in the main provider's office helped you? If more than one person helped you, mark the person who helped you most often in the last 12 months.

Your child's main provider

Another doctor or nurse in the main provider's office

A clerk or receptionist in the main provider's office

A care coordinator in the main provider's office

A social worker in the main provider's office

A care manager or case manager in the main provider's office

Someone else in the main provider's office

13. In the last 12 months, did the person in the main provider's office who helped you with managing your child's care...

	<u>Yes Definitely</u>	<u>Yes Somewhat</u>	<u>No</u>
a. Know the important information about your child's health and care needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Seem informed and up-to-date about the care your child got from other providers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Support your decisions about what is best for your child's health and treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Help you to get appointments to visit other providers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Help you to get special medical equipment your child needed like a special bed, wheelchair, or feeding tube supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





14. In the last 12 months, did you know how to contact the person who helped you with managing your child's care when you needed help or had a question?
- Yes
- No
15. **In the last 3 months**, did this person contact you without you getting in touch with them first?
- Yes
- No → **If No, go to #19**
16. How did he or she contact you? Please mark one or more.
- During a visit to the main provider's office
- By telephone
- By email
- By mail
- Some other way
17. In the last 3 months, when the person in the main provider's office who helped you manage your child's care contacted you, how often did he or she ask if you had any concerns about your child's health or treatment?
- Never
- Sometimes
- Usually
- Always
18. In the last 3 months, when the person in the main provider's office who helped you manage your child's care contacted you, how often did he or she ask if your child's health had changed in any way?
- Never
- Sometimes
- Usually
- Always
19. Overall, how often did the main provider's office give you the help you needed to manage your child's care or treatment from different doctors or care providers **in the last 12 months**?
- Never
- Sometimes
- Usually
- Always



20. Overall, how satisfied or dissatisfied were you with help from the main provider's office to manage your child's care or treatment in the last 12 months?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

### **Your Child's Care from Specialists**

The next few questions ask about your experiences with getting care for your child from specialists.

21. Specialists are doctors like surgeons, heart doctors, allergy doctors, mental health doctors, and other doctors who specialize in one area of health care. During the last 12 months, did the main provider tell you that your child needed to see a specialist?

- Yes
- No → **If No, go to #25**

22. Did the person in the main provider's office who helped you with managing your child's care contact you to make sure your child got an appointment to see a specialist?

- Yes
- No
- I did not get help managing my child's care from the main provider's office

23. In the last 12 months, did you try to make any appointments with specialists for your child?

- Yes
- No → **If No, go to #25**

24. In the last 12 months, how often was it easy to get appointments with specialists for your child?

- Never
- Sometimes
- Usually
- Always





### Getting Community Services for You and Your Child

The next few questions ask about your experiences with getting community services for you or your child.

25. **Community services** are services to help maintain your and your child's health and well-being, which may or may not be ordered by one of your child's doctors. This can include things like home health care, early intervention programs, respite care, help with transportation, and parent or caregiver support services. In the last 12 months, did you or your child need or use community services?
- Yes
- No → **If No, go to #29**
26. Did the person in the main provider's office who helped you with managing your child's care help you to get the community services you or your child needed?
- Yes
- No → **If No, go to #29**
27. Overall, how often did the main provider's office help you to get the community services you and your child needed in the last 12 months?
- Never
- Sometimes
- Usually
- Always
28. Overall, how satisfied or dissatisfied were you with help from the main provider's office to get community services in the last 12 months?
- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied



## Getting Summaries of Your Child's Visits or Hospital Stays

The next set of questions asks about different ways in which you might get information about the care your child is receiving. We are interested in summaries you might have received after visiting the main provider's office or after your child was in the hospital.

29. A **written visit summary** sums up what happened during your child's visit to a health care provider. A written visit summary can be available on paper, on a web site, through an app, or sent by email.

In the last 12 months, did anyone at the main provider's office give you a written visit summary after your child's visits?

- Yes  
 No → **If No, go to #33**

30. How often did the written visit summaries you got from the main provider's office include...

	<u>Never</u>	<u>Sometimes</u>	<u>Always</u>
a. A list of your child's health problems at the time of the visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. An up-to-date list of all the prescription medicines your child is taking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. An up-to-date list of all the <b>over the counter medicines</b> your child is taking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. A list of your child's allergies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. The names of all the specialist doctors who help care for your child?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. The plan for follow-up care for your child after the visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. What to do if your child had a problem after the visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. In the last 12 months, how often was the written visit summary you got from the main provider's office easy to understand?

- Never  
 Sometimes  
 Always



32. In the last 12 months, how often was the written visit summary you got from the main provider's office useful to you and your family?

- Never  
 Sometimes  
 Always

33. Has your child had an overnight hospital stay in the last 12 months?

- Yes  
 No → **If No, go to #38**

34. A written hospital stay summary sums up all that happened during your child's hospital stay. A written hospital stay summary can be available on paper, on a web site, through an app, or sent by email.

**The last time your child was in the hospital**, did your child's doctor, nurse, or other hospital staff give you a written hospital stay summary on the day your child left the hospital?

- Yes  
 No → **If No, go to #37**

35. Did the written hospital stay summary you got include...

	<u>Yes</u>	<u>No</u>
a. A list of the health problems your child had when he or she left the hospital?	<input type="checkbox"/>	<input type="checkbox"/>
b. A list of all the prescription medicines your child was taking when he or she left the hospital?	<input type="checkbox"/>	<input type="checkbox"/>
c. A list of all the <b>over the counter medicines</b> your child was taking when he or she left the hospital?	<input type="checkbox"/>	<input type="checkbox"/>
d. A list of your child's allergies?	<input type="checkbox"/>	<input type="checkbox"/>
e. The names of all the specialist doctors who helped care for your child during the hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>
f. What the planned follow-up care was for your child after the hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>
g. Who to call if your child had problems after the hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>

36. Was the information in the written hospital stay summary you got easy to understand?

- Yes, definitely  
 Yes, somewhat  
 No



37. Hospital rounds are the daily visits the health care team makes to patients in the hospital to check up on how they are doing and how well the treatment is working, and what the plan for the day will be. Nurses, doctors, medical students and other health care providers may join hospital rounds to discuss the plan for the day for every patient.

**The last time your child was in the hospital**, did any of your child's doctors or nurses invite you to take part in hospital rounds?

Yes

No

### **Getting Information about Your Child's Health and Health Care In Between Visits**

In addition to information you may get after a visit or a hospital stay, some providers make information available through a web site or an app. We are interested in your experiences with this way of getting information about your child's health and health care.

38. **In the last 12 months**, did the main provider's office have a web site or app you could use between visits to look up information about your child's visits and health care?

Yes

No → **If No, go to #43**

I don't know if my child's main provider's office has a web site or app → **If Don't know, go to #43**

39. In the last 12 months, did the main provider's web site or app have a list of the **shots or immunizations** your child has received?

Yes

No

My child has not received any shots or immunizations in the last 12 months

I don't know if the web site or app for my child's main provider's office has a list of my child's shots or immunizations

40. In the last 12 months, did the main provider's web site or app have a list of your child's **medications**?

Yes

No → **If No, go to #43**

My child has not taken any medications in the last 12 months → **If No medications, go to #43**

I don't know if the web site or app for my child's main provider's office has a list of my child's medications → **If Don't know, go to #43**





41. Was the list of your child's medications up-to date?
- Yes
  - No
  - I did not look at my child's list of medications on the web site or app → **If Didn't look, go to #43**
  - I don't know if the list of my child's medications on the main provider's web site or app is up-to-date → **If Don't know, go to #43**
42. Did the information on the web site or app include instructions about dosages, that is how much of each medication you should give your child and how often you should give them?
- Yes
  - No
  - I did not look at my child's list of medications on the web site or app
  - I don't know

### **Your Child's Care Plans**

The next set of questions asks about three different types of written care plans the main provider may have created for your child: shared care plans, emergency care plans, and transition care plans. We are interested in your experiences, if any, with these different types of plans.

43. A **shared care plan** is a written document that contains information about your child's active health problems, medicines he or she is taking, special considerations that all people caring for your child should know, goals for your child's health, growth and development, and steps to take to reach those goals.

Has the main provider created a shared care plan for your child?

- Yes
  - No → **If No, go to #50**
44. Did the main provider ask you to take part in creating your child's shared care plan?
- Yes
  - No
45. When was the shared care plan first created?
- Within the last 12 months → **If Last 12 months, go to #48**
  - More than 12 months ago
  - I don't know



46. Has the shared care plan been **updated** in the last 12 months?

- Yes
- No → **If No, go to #48**
- I don't know → **If Don't know, go to #48**

47. Did the main provider ask you to take part in updating your child's shared care plan?

- Yes
- No

48. Do you have a copy of your child's shared care plan?

- Yes
- No → **If No, go to #50**

49. In the last 12 months, has the main provider or anyone from the main provider's office talked with you about the progress your child was making toward the goals written in his or her shared care plan?

- Yes
- No
- My child's shared care plan does not have written goals

### **Your Child's Emergency Care Plan**

50. An **emergency care plan** is a written document that contains important information about your child's health, treatment and medications. It also includes special considerations that all people caring for your child should know, for example, how your child lets you know he or she is in pain, or how to communicate with your child if he or she can't hear or speak. Families often bring the emergency care plan when they take a child to an emergency room or urgent care clinic.

Has the main provider created an emergency care plan for your child?

- Yes
- No → **If No, go to #59**

51. Did the main provider ask you to take part in creating your child's emergency care plan?

- Yes
- No





52. When was the emergency care plan for your child first created?

- Within the last 12 months → **If Last 12 months, go to #55**
- More than 12 months ago
- I don't know

53. Has the emergency care plan been **updated** in the last 12 months?

- Yes
- No → **If No, go to #55**
- I don't know → **If Don't know, go to #55**

54. Did the main provider ask you to take part in updating your child's emergency care plan?

- Yes
- No

55. Do you have a copy of your child's emergency care plan?

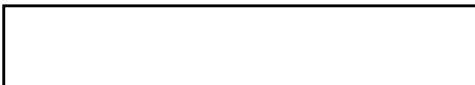
- Yes
- No → **If No, go to #57**

56. Does your child's emergency care plan include...

	<u>Yes</u>	<u>No</u>
a. A current list of your child's health problems or conditions?	<input type="checkbox"/>	<input type="checkbox"/>
b. An up-to-date list of all the prescription medicines your child is taking?	<input type="checkbox"/>	<input type="checkbox"/>
c. An up-to-date list of all the <b>over the counter medicines</b> your child is taking?	<input type="checkbox"/>	<input type="checkbox"/>
d. A list of your child's allergies?	<input type="checkbox"/>	<input type="checkbox"/>
e. Instructions for emergency care staff to use to contact your child's main provider?	<input type="checkbox"/>	<input type="checkbox"/>
f. Information on how to tell when your child is in pain?	<input type="checkbox"/>	<input type="checkbox"/>

57. In the last 12 months, did you and the main provider talk about how much and what kinds of life-saving actions your family wants for your child in the event of an emergency?

- Yes
- No → **If No, go to #59**





58. Were your family's instructions about how much and what kinds of life-saving actions to take included in your child's emergency care plan?

- Yes  
 No  
 I don't know

### **Your Child's Transition Plan**

59. If your child is at least 15 years old, we are interested in your experiences with making plans for your child's care when he or she becomes an adult. This is sometimes called a transition plan.

Is your child age 15 or older?

- Yes  
 No → **If No, go to #66**

60. Has the main provider created a written transition plan that summarizes how your child's care will change and how it will stay the same when he or she becomes an adult?

- Yes  
 No → **If No, go to #66**  
 I don't know → **If Don't know, go to #66**

61. Did you take part in creating the transition plan for your child?

- Yes  
 No

62. When was the transition plan first created?

- Less than 12 months ago → **If Less than 12 months, go to #65**  
 12 or more months ago  
 I don't know

63. Has this plan been reviewed and **updated** in the last year?

- Yes  
 No → **If No, go to #65**  
 I don't know → **If Don't know, go to #65**





64. Did the main provider ask you to take part in updating the transition plan for your child's care when he or she becomes an adult?

Yes

No

65. Do you have a copy of the transition plan for your child's care?

Yes

No

### **Your Rating of Your Child's Main Provider**

66. We are interested in your overall rating of the main provider. Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate the main provider?

0 Worst provider possible

1

2

3

4

5

6

7

8

9

10 Best provider possible

### **Your Child's Experiences in School**

The next set of questions asks about your child's experiences in school.

67. **In the last 12 months**, did your child attend school?

Yes

No → **If No, go to #76**

68. Because of his or her health condition does your child have any difficulty learning, understanding, or paying attention in class?

Yes

No → **If No, go to #70**





69. In the last 12 months, did anyone from the main provider's office contact staff at your child's school to make sure they understood how your child's health condition affected his or her ability to learn, understand or pay attention in class?
- Yes
- No
- I don't know
70. During the last 12 months, how would you describe your child's grades in school?
- Below average (D's or F's)
- Average (C's)
- Good (B's)
- Very good (A's and B's)
- Excellent (A's)
- My child did not get grades in school in the last 12 months
71. **In the last 4 weeks of the school year**, how did your child do in math?
- Poor
- Fair
- Good
- Very good
- Excellent
- My child did not take math in the last 4 weeks of school
72. In the last 4 week of the school year, how did your child do in his or her homework?
- Poor
- Fair
- Good
- Very good
- Excellent
- My child did not have homework in the last 4 weeks of school



73. In the last 4 weeks of the school year, how did your child do in reading?

- Poor
- Fair
- Good
- Very good
- Excellent
- My child did not read in the last 4 weeks of school

74. In the last 4 weeks of the school year, how did your child do in remembering things he or she learned in school?

- Poor
- Fair
- Good
- Very good
- Excellent
- My child is not able to communicate what he or she has learned in school

75. In the last 4 weeks of the school year, how many days did your child's health keep him or her out of school all or most of the day?

- No days
- 1 to 3 days
- 4 to 7 days
- More than 7 days

**Your Child's Health and Mood**

76. In general, would you say your child's health is:

- Poor
- Fair
- Good
- Very good
- Excellent

77. In general, would you say your child's quality of life is:

- Poor
- Fair
- Good
- Very good
- Excellent





78. In general, how would you rate your child's physical health?

- Poor
- Fair
- Good
- Very good
- Excellent

79. In general, how would you rate your child's mental health, including mood and ability to think?

- Poor
- Fair
- Good
- Very good
- Excellent

### Managing Your Child's Health Care

The next set of questions asks about the time you spend managing your child's health care and other services.

80. Have you or other family members stopped working because of your child's health?

- Yes
- No

81. Have you or other family members cut down on the hours you work because of your child's health?

- Yes
- No

82. **In the last 4 weeks**, about how many hours per week did you spend managing the care your child was getting from different doctors or care providers, including making sure that information was shared between all of these providers?

- Less than 1 hour each week
- 1 to 10 hours each week
- 11 to 20 hours each week
- 21 to 39 hours each week
- More than 40 hours each week

83. How stressful is it for you to manage your child's care?

- Very stressful
- Somewhat stressful
- A little stressful
- Not at all stressful



## About You and Your Child

This last set of questions is about you and your child. This information will help us to describe the parents and children who take part in this study.

84. How well do you speak English?

- Very well
- Well
- Not well
- Not at all well

85. Do you speak a language other than English at home?

- Yes
- No → **If No, go to #92**

86. What is the language you speak at home?

- Spanish
- Some other language



*Please print other language:*

87. Do you prefer to talk with your child's doctors and care providers in English or in another language?

- English → **If English, go to #92**
- Another language

88. **In the last 12 months**, did the main provider speak to you in the language you prefer?

- Yes
- No

89. In the last 12 months, did anyone in the main provider's office speak to you in the language you prefer?

- Yes
- No



90. A medical interpreter is a professional who helps you talk with doctors and other providers who do not speak your language. The interpreter can do this over the phone or in-person. In the last 12 months, how often did you need an interpreter during a visit to the main provider?

No visits → **If No visits, go to #92**

Some visits

Most visits

All visits

91. When you needed a professional interpreter during a visit to the main provider, how often was an interpreter available?

Never

Sometimes

Usually

Always

92. Is **your child** of Hispanic or Latino origin or descent?

Yes, Hispanic or Latino

No, not Hispanic or Latino

93. What is **your child's** race? Mark one or more.

White

Black or African American

Asian

Native Hawaiian or Other Pacific Islander

American Indian or Alaska Native

Other

94. What is **your** age?

Under 18

18 to 24

25 to 34

35 to 44

45 to 54

55 to 64

65 to 74

75 or older



95. Are **you** male or female?

- Male
- Female

96. Are **you** of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

97. What is **your** race? Mark one or more.

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaska Native
- Other

98. What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

99. How are you related to your child?

- Mother or father
- Grandparent
- Aunt or uncle
- Older brother or sister
- Other relative
- Legal guardian
- Some other way



*Please print:*



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100. Did someone help you complete this survey?

- Yes
- No → **If No, go to #102**

101. How did that person help you? Mark one or more.

- Read the questions to me
- Wrote down the answers I gave
- Answered the questions for me
- Translated the questions into my language
- Helped in some other way



*Please print:*

### **More Information About Additional Parts of This Study**

The letter we mailed you with this survey listed two additional parts of this study. Study researchers at Seattle Children's Research Institute, RAND Corporation and Minnesota Department of Human Services would like your child's main provider to share some of the information in your child's medical records, to get more detailed information on the care or services your child received. These researchers would also like to have your child's Medical Assistance or MinnesotaCare visit and cost information. Having these additional pieces of information gives researchers a full picture on your child's health, care needs and the care and services your child gets.

102. Do you give your permission for Seattle Children's Research Institute to contact you to give you information about the medical records part of this study?

- Yes
- No

103. Do you give your permission for Seattle Children's Research Institute to contact you to give you information about the Medical Assistance or MinnesotaCare visit and cost information part of this study?

- Yes
- No

**Thank you for answering this survey.**

**Please put it in the postage-paid envelope and return it to:**

**RAND Corporation  
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