

SUPPLEMENT A. Patient Demographics

| | No. (%) ^a |
|----------------------------------------------------|----------------------|
| Age, y | |
| 0 – 23 mo | 4 (24) |
| 2 – 4 | 4 (24) |
| 5 – 12 | 5 (29) |
| 13 – 17 | 4 (24) |
| Female sex | 2 (12) |
| Race/ethnicity | |
| White | 12 (71) |
| Hispanic | 2 (12) |
| Other/Mixed | 3 (18) |
| Residence | |
| Greater metropolitan area | 10 (59) |
| In-state | 6 (35) |
| Out-of-state | 1 (6) |
| No. of health conditions | |
| 0 – 5 | 2 (12) |
| 6 – 10 | 3 (18) |
| 11 – 15 | 9 (53) |
| > 15 | 3 (18) |
| No. of locations where patient receives care | |
| 0 – 5 | 12 (71) |
| 6 – 10 | 5 (29) |
| No. of individuals involved in patient's care team | |
| 6 – 10 | 3 (18) |
| 11 – 15 | 4 (24) |
| 16 – 20 | 2 (12) |
| > 20 | 8 (47) |
| Frequency of PCP visits | |
| Seen often | 10 (59) |
| Seen rarely | 7 (41) |
| No. of hospitalizations in past year | |
| None | 2 (12) |
| Once | 1 (6) |
| 2 – 4 | 7 (41) |
| 5 – 10 | 6 (35) |
| > 10 | 1 (6) |
| Has medical equipment needs | 16 (94) |
| No. of caregivers at home | |
| ≤ 2 caregivers | 7 (41) |
| > 2 caregivers | 10 (59) |

Abbreviations: PCP = primary care provider

^aSum may not equal 100% due to rounding.

SUPPLEMENT B: Initial Interview Guide for Caregivers

1. Does your child have a care plan like what I described above or similar to this document I showed you? **[Record answer]**
 - Yes → Skip to Q4
 - No
 - I'm not sure
2. If a care plan could be created for your child, would you want one for your child? **[Record answer]**
 - Yes
 - No
 - I'm not sure
3. Please tell me more about why you chose that answer. *Probes: Why would you want one? Why would you not one? What would help you decide on whether you wanted a care plan for your child?* **[Skip to Q5]**
4. Tell me about your child's care plan. *Probes: Who created your child's care plan? Where is it stored? What type of information is in your child's care plan? Do you have access to your child's care plan? Can you change information in your child's care plan? How often do you use it – daily, weekly, once a month, once every 6 months, never? How often is your child's care plan updated? Who updates it?*
5. Are there other ways besides a care plan that you organize and share all your child's health information? **[Record answer]**
 - Yes
 - No → Skip to Q7
 - I'm not sure → Skip to Q7
6. Tell me more about how you organize and share your child's health information. *Probes: Where do you keep this information? How is it organized? How do you share this information with doctors? How often do you refer to this information?*
7. Thinking back to your experience [coming into the emergency department or hospital][leaving the hospital] this time with your child, can you describe how information about your child and his/her health was shared between you and your child's providers?
8. What were some of the things that made sharing this information easy? What was difficult?
9. How do you think a care plan that was available in the “cloud” would have been helpful to share information about your child and his/her health when you [came into the emergency department or hospital][left the hospital]?
10. What kind of problems do you think there would be with a cloud-based care plan in this situation?

11. Ok, let's get more specific about what these care plans would look like. What information should be included in these care plans? *Probes: Medications with dosages/times, care team members and contact information, a list of child's medical conditions, etc.* **[Record a list of this content information.]**
12. What other things should be included? *Probe: Thinking back to when you [came into the emergency department or hospital][left the hospital] with your child, what did you [want the doctors to know][want to know] about your child and his/her health?* **[Add to the list of content information from Q11]**
13. If you had to pick three of the most important things to include in the care plan from this list you gave me, what would they be? **[Show caregiver the list and have them pick three. Record this answer.]**
14. Now, I'm going to have you use your imagination a bit. If your child had a cloud-based care plan, how would [you want to share this information with the doctors taking care of your child when you came into the hospital][you want to receive information from doctors when you left the hospital]? *Probes: Have them log into a protected web page? Through a patient portal? Part of the electronic health record? Through your phone?*
15. Would you want access to a cloud-based care plan for your child? **[Record answer]**
- Yes
 - No
 - I don't know
16. Please tell me more about why you chose that answer. *Probes: Why would you want access? Why would you not want access?*
17. If yes, how would you want to access your child's cloud-based care plan? *Probe: On a computer? On your smartphone? On a tablet? Through a patient portal?*
18. Who else should have access to your child's cloud-based care plan? *Which doctors? Which ancillary staff – therapists, school, home health services? Nurses? Which family members?*
19. Would you want to be involved in updating your child's cloud-based care plan? **[Record answer]**
- Yes
 - No
 - I don't know
20. Please tell me more about why you chose that answer. *Probe: Tell me why or why not?*
21. Who else should be involved in updating your child's cloud-based care plan? *Probe: Which doctors? Which family members? Care coordinators?*

22. Who should be involved in creating a cloud-based care plan for your child? *Probe: Which doctors – PCP, hospital doctors, specialists (which specialist)? Which family members? Care coordinators?*
23. When and where is the best time to create a cloud-based care plan? *Probe: PCP office visit? Specialist office visit – which specialist? Separate visit with care coordinator? In the hospital? At home?*
24. We're going to do a quick drawing exercise to get an idea of what a cloud-based care plan may look like. This is sometimes difficult to do without actually seeing what it is, but I want you to use your imagination as much as possible. If you don't want to draw, I'm happy to do that part, as you talk through it. Let's think back to those three important things that should be included in a care plan. Let's pick one. Can you draw for me how you would want this to look like if it was on a computer screen or smartphone? Please walk me through what you're drawing so we can record what you're thinking on the audio-recorder. *Probe: What features would it have if you could tap on a button or click on part of the screen?* **[If participant is very hesitant about doing this part, ok to skip or just have them talk through a scenario of what it would look like if they showed up in the emergency department]**
25. Thinking back to your experience [coming into the emergency room or hospital][leaving the hospital] with your child, how do you think you would have used this design you came up with in your interactions with the doctors?
26. Now that we've thought about these cloud-based care plans some more, describe how a cloud-based care plan may be useful [when you come into the emergency room or hospital with your child][when you left the hospital with your child]?
27. Describe some problems that you may encounter when using a cloud-based care plan [when you come into the emergency room or hospital with your child][when you leave the hospital you're your child]?

SUPPLEMENT C: Initial Interview Guide for Healthcare Providers

1. Did your patient have a care plan when [they came into the hospital][came to see you for their follow-up visit]?
 - Yes
 - No → Skip to Q3
 - I'm not sure → Skip to Q3

2. Please describe your patient's care plan. *Probes: Who created the care plan? Where was it stored? What type of information was in your patient's care plan? Did you have access to your patient's care plan? Could you change information in your patient's care plan if you wanted to? Did you use your patient's care plan when they came into the hospital? Do you know when your patient's care plan was last updated? Do you know who updated your patient's care plan?*

3. If your patient did not have a care plan, did the parents have any other ways that they organized or stored their child's health information? **[Record answer]**
 - Yes
 - No → Skip to Q5
 - I'm not sure → Skip to Q5

4. Tell me more about how your patient's information was stored? *Probes: Did the parents have a binder, notebook or their own electronic document? Where did they keep this information? How was it organized? Was it useful for you when they came into the hospital? Why or why not?*

5. **[If no care plan available for patient, then ask]** If a care plan could be created for your patient, would you have used it when they [came into the emergency department or hospital][came in for their follow-up visit]? **[Record answer]**
 - Yes
 - No
 - I'm not sure

6. **[If not care plan available for patient, then ask provider to expand on their answer to #5]** *Probes: How would you have used it? Why would you not use one? What would help you decide on whether you used a care plan for this patient?*

7. Thinking back to your experience with this patient [in the emergency department or hospital][at the follow-up visit], can you describe how the family shared information with you about their child and their health conditions?

8. **[For hospital providers only]** What were some of the things that made sharing this information easy? What was difficult?
9. **[For follow-up providers only]** Describe other ways you were given information about the patient's conditions and how to manage their care.
10. **[For follow-up providers only]** What was helpful to you about how the information you were given about the patient was presented to you? What was not helpful?
11. **[For follow-up providers only]** What kinds of information did you ideally want to have?
12. How do you think a care plan that was available in the "cloud" would have been helpful to share this type of information with you when your patient [came into the emergency department or hospital][came in for a follow-up visit]?
13. What kind of problems do you think there would be with a cloud-based care plan?
14. Ok, let's get more specific about what these care plans would look like. What information should be included in these care plans? *Probes: Medications with dosages/times, care team members and contact information, a list of child's medical conditions, sick plans, etc.*
[Record a list of this content information]
15. What other things should be included? *Probe: Thinking back to when your patient [came into the emergency department or hospital][came in for a follow-up visit], what information did you want to know about this patient?* **[Add to the list of content information from Q11]**
16. If you had to pick three of the most important things to include in the care plan from this list you gave me, what would they be? **[Show provider the list and have them pick three. Record this answer.]**
17. Would you have wanted access to a cloud-based care plan for this patient? *Probe: Tell me why or why not?*
18. If your patient had a cloud-based care plan, how would you want to access the patient's cloud-based care plan? *Probes: Log into a protected web page? Through a patient portal? Access it through the electronic health record? On your smartphone? On a tablet?*
19. Who else should have access to the patient's cloud-based care plan? *Probes: Which doctors? Which ancillary staff – therapists, school, home health services? Nurses? Which family members?*

20. Would you want to be involved in updating the patient's cloud-based care plan? *Probe: Tell me why or why not?*
21. Who else should be involved in updating your patient's cloud-based care plan? *Probe: Which doctors? Which family members? Care coordinators?*
22. Who should be involved in creating a cloud-based care plan for your patient? *Probe: Which doctors – PCP, hospital doctors, specialists (which specialist)? Which family members? Care coordinators?*
23. When is the best time to create a cloud-based care plan? *Probe: PCP office visit? Specialist office visit – which specialist? Separate visit with care coordinator? In the hospital? At home?*
24. Thinking back to those three important things that should be included in a care plan. Can you draw for me how you would want this to look if it was on a [use preferred location that provider mentioned in Q18: e.g. webpage, smartphone, EHR]? Please walk me through what you're drawing so we can record what you're thinking on the audio-recorder. *Probe: What features would it have if you could tap on a button or click on part of the screen?*
25. Thinking back to your experience with this patient [in the emergency room or hospital][at their follow-up visit], how do you think you would have used this design you came up with in your interactions with the family?
26. Now that we've thought about these cloud-based care plans some more, describe how a cloud-based care plan may be useful when a patient with medical complexity comes [into the emergency room or hospital][in for a follow-up visit after a hospitalization]?
27. Describe some problems that you may encounter when using a cloud-based care plan when a patient with medical complexity comes [into the emergency room or hospital][in for a follow-up visit after a hospitalization]?