

Table S1. Survey Tool

Please answer the questions about the child who is listed on this survey. When we refer to your “doctor” in the survey, we are referring to your healthcare provider (doctor or nurse practitioner) in the Special Care Clinic.

Parent/Caregiver Information

Parent/Caregiver Name: _____

Parent/Caregiver Date of Birth: _____

Parent/Caregiver Emergency Contact: _____

Parent/Caregiver Phone Number: _____

Parent/Caregiver Address:

Street _____

City, State, Zip Code: _____

Child's Name: _____

The following questions will assess your **understanding** of your child's medications:

1) Let's do this one together. Using the oral syringe I just provided to you, measure 4 mL.

- Caregiver is able to accurately measure
- Caregiver is unable to accurately measure

2) Let's try another one. Using the oral syringe I just provided to you, measure 0.35 mL.

- Caregiver is able to accurately measure
- Caregiver is unable to accurately measure

3) How many different **medications** does your child take in a typical day?

- None (0)
- One or two (1-2)
- Three to Five (3-5)
- Six to Ten (6-10)
- Eleven to Fifteen (11-15)
- Greater than Fifteen (>15)

4) List the names of all of the medications your child is currently taking to treat each condition listed below:

Condition being treated

1. _____

Medication(s)

1. _____

2. _____

3. _____

4. _____

Others. _____

2. _____

Medication(s)

1. _____

2. _____

3. _____

4. _____

Others. _____

The following questions relate to the following complex medication_____. Please answer the question about this medication only.

5) What is the reason/indication why your child is taking this medication?

6) How do you administer this medication to your child? (ex. describe the administration technique including dosage form, dose, and site of administration, and frequency)

Formulation (e.g., tablet strength or concentration) _____

Dose (mg and/or mL) _____

Frequency (e.g., how many times per day) _____

Route of Administration (e.g., by mouth, gtube) _____

7) For the following statements, please rate how strongly you agree or disagree with the statement:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I understand the possible side effects of my child's medications					
I understand what to do if my child experiences a side effect to a medication					
I understand what to do if my child misses a dose of a medication					
I know if/when to call my physician regarding my child's medications					
I am satisfied with the explanations I was given regarding my child's medications					

8) Please provide any additional comments or questions you would like to make about your overall understanding of your child's complex medication regimen:

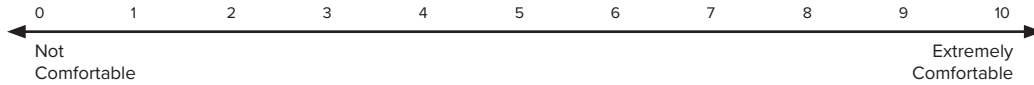
The following questions will assess your **confidence** related to your child's medications:

9) For the following statements, please rate how strongly you agree or disagree with the statement

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I feel confident that the number of medications my child is taking is needed					
I am confident I understand why my child was prescribed each of the medications					
I am confident in my abilities to correctly administer all of the medications my child is taking					
I am confident in my abilities to accurately measure liquid medications					
I am confident in my abilities to accurately administer injectable medications to my child					
I am confident in administering partial tablets or crushed tablets to my child					
If my provider said it was possible, I would be willing to stop one or more of the regular medications my child is taking					

10) Please provide any additional comments you would like to make about your overall confidence related to administering your child's complex medication regimen.

11) On a scale of 0 to 10, with 0 meaning not comfortable at all and 10 being extremely comfortable, mark an "X" on the line to show how comfortable would you be if a clinical pharmacist was involved in stopping one or more of your child's regular medications and provided follow-up (informing your doctor of the progress)?



12) If one or more of your child's regular medications was stopped, what follow-up would you like? (You may select more than one answer).

- Face-to-face appointment
- No planned follow-up needed
- Phone call
- Written information sent in the mail
- Written information sent by e-mail
- Other, please specify _____

The questions below are about you and your family. (For each question below, please select the ONE best answer)

13) Does your child receive home-nursing?

- Yes
- No

14) If you answered yes to question #13, how many hours per day does your child receive home-nursing?

15) What percentage of your child's medication doses are administered by a family member at home?

- 0-25%
- 25-50%
- 50-75%
- 75-100%

16) How are you related to the child followed in the Special Care Clinic?

- Biologic Mother
- Biologic Father
- Step Mother, Foster Mother or Adoptive Mother
- Step Father, Foster Father or Adoptive Father
- Guardian
- Other

17) What is the primary language spoken in your home?

- English
- Spanish
- Other (please write in) _____

18) What is the highest grade or level of school that you have finished?

- 8th grade or less
- Some high school
- High school graduate/GED
- Some college
- 4-yr college graduate
- More than college graduate

19) What is your race? Please mark one or more.

- White
- Black or African-American
- Hispanic or Latino
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native
- Other (please write in): _____

20) What is your current yearly family income?

- Less than \$15,000
- \$15,000-30,000
- \$30,001-60,000
- \$60,001-100,000
- Over \$100,000

Survey adapted from the following references:

1. Okuyan B, Sancar M, Izzettin FV. Assessment of medication knowledge and adherence among patients under oral chronic medication treatment in community pharmacy settings. *Pharmacoepidemiology and Drug Safety*. 2013;22:209-214.
2. Reeve E, Wiese MD, Hendrix I, Roberts MS, Shakib S. People's attitudes, beliefs, and experiences regarding polypharmacy and willingness to deprescribe. *J Am Geriatr Soc*. 2013;61:1508-1514.