

## Interview Guide for Transition of Care Provider Interviews

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Staff: 1 interviewer

Materials: color copy of SMART model, definitions of SMART components, 2 audio-recording devices

Expected interview duration: 45 minutes

*During the interview, <<condition>> should be replaced with the specific health condition that is the topic of the interview. For interviews with generalists, <<condition>> should be replaced with “chronic diseases.”*

*AYA is used in the interview guide to abbreviate “Adolescents and Young Adults.” When performing the interview, it should be spoken as “Adolescents and Young Adults.”*

*Interviews will be scheduled over email or phone at a time convenient to the interviewee.*

*The interviews may take place in person or over the phone. For interviews that take place over the phone, the image of the SMART model should be emailed to the interviewee prior to the interview. Phone interviewees should be informed that the interview will reference a document, so they should take the interview phone call in a place where they can reference the document either printed out ahead of time or viewed on screen. They should be discouraged from taking the interview phone call while driving or otherwise preoccupied.*

### **I. Introduction to study and interviewer**

#### ***For phone interviews:***

*Call at the time agreed upon. If no answer, call again in 5 minutes. If no answer, call again in 5 minutes. If no answer, send email to reschedule. Do not leave voice mail.*

*If the provider answers the call: Hello. My name is \_\_\_\_\_, and I’m calling from The Children’s Hospital of Philadelphia regarding the Transition of Care Study. Does this time still work for our 45 minute interview?*

*If NO: Is there another time that would be better for me to call back?*

*If YES: Proceed.*

#### ***For both phone and in-person interviews:***

Thanks for taking the time to speak with me today. As you know, I’d like to talk with you about the transition process from pediatric to adult care among AYA with special healthcare needs, including <<condition>>. During the interview, I will distinguish between transition and

32 transfer. By transition, I mean the longitudinal process of **preparing** AYAs to change their care  
33 providers from pediatric-focused to adult-focused physicians. I will refer to transfer as the  
34 actual exit from pediatric care into adult care.

35 We are conducting interviews with a variety of providers on the topic of transition as part of a  
36 research study. Our goals are to identify important markers of transition success and failure  
37 that can be addressed using a smartphone app we are developing for transitioning AYA. We are  
38 seeking your input as an expert in <<condition>>, and are not assessing or judging you or your  
39 practice based on the information you share about the transition process. Your participation is  
40 completely voluntary.

41 First, I'd like to ask for your permission to proceed before the interview questions begin. Let me  
42 remind you that this interview will be audiotaped.

43 *If permission is given, begin audiotaping now. Prior to the introduction of the interview, start*  
44 *the date/time and names of interviewer and subject at the beginning of the recording.*

## 45 **II. Questions about interviewee**

46 Now I will proceed to the interview questions.

47 First, could you describe your job to me?

48 Great, thanks.

49 *If any of the following were not already answered above:* Now I have some specific questions.

50 What is your current job title?

51 How many years have you been in practice caring for adolescents and young adults? This may  
52 include years in training (e.g. residency, fellowship, internship, etc).

53 What percentage of your time is devoted to patient care?

54 Could you tell me about your interest or experience working with adolescents and young adults  
55 with <<condition>> who you receive from pediatric care?

56 Is any of your time devoted to studying or improving the transition process for adolescents and  
57 young adults? How much?

## 58 **III. General questions about transition process**

59 Now, I'd like to ask you about how the transition intake process works for patients with  
60 <<condition>> in your practice.

61 Does your institution have established relationships with any pediatric centers, such as CHOP,  
62 that transfer adolescents and young adults to you?

63 **IV. Examples of successful transition**

64 Ok great. Now, could you tell me about a time when a patient with <<condition>> had a very  
65 successful transition and transferred smoothly to adult care with you? Please refrain from using  
66 patient names when describing it.

67 *Goal is quality of anecdotes over quantity. If they tell you one really fantastic anecdote that*  
68 *adequately addresses all of the points, that is fine. If they tell one short story that does not*  
69 *adequately address the points or a story about a very unusual circumstance, ask for other*  
70 *examples. Move on when all the points have been addressed.*

71 What outcomes made it clear that the process was successful?

72 What did you observe in particular about the patient that may have contributed to their  
73 success?

74 What did you observe about the patient's family that may have contributed to their success?

75 Were there any specific milestones the patient or family met? If so, what were they?

76 What facilitated them meeting those milestones or having a successful transfer to adult care  
77 and staying in adult care with you?

78 What threatened their ability to meet those milestones or have a successful transfer to adult  
79 care and staying in adult care?

80 As their provider, how did you play a role in their successful transition and transfer to adult  
81 care?

82 *Summarize their response.* To summarize that, I've heard you say that your patient had a  
83 successful transition and transferred smoothly to adult care as evidenced by \_\_\_\_\_.  
84 The key factors that contributed to their success were \_\_\_\_\_. Thanks for sharing  
85 that story. Are there other outcomes might define a successful transition and transfer process  
86 for patients with <<condition>>? What are they?

87 **V. Examples of unsuccessful transition**

88 Now, could you tell me about a time when a patient with <<condition>> who you were caring  
89 for had a transition that did not go smoothly, and perhaps resulted in an adverse medical  
90 outcome either prior to, or after transfer to adult care?

91 *Examples of adverse medical outcomes may be given if they struggle, but do not give them*  
92 *outcome examples for the specific disease we are asking them about. Give them examples from*

93 *another disease. We want them to come up with the examples for their disease. For diabetes,*  
94 *examples might include a clinically important increase in hemoglobin A1c, hospitalization for*  
95 *ketoacidosis, or signs of end organ damage.*

96 *If provider still struggles to come up with a situation with adverse medical outcome, say That's*  
97 *fine. Could you describe a situation in which the transition and subsequent transfer to adult*  
98 *care was unsuccessful but did not necessarily result in an adverse medical outcome? By*  
99 *unsuccessful, I mean that the transition was challenging or that the patient did not successfully*  
100 *connect with you or another adult care provider. Examples may include patient dropped out of*  
101 *care altogether (and the status is unknown), or patient refused to transfer to an adult provider*  
102 *and is still with a pediatric or adolescent provider.*

103 What did you observe about the patient that may have contributed to an unsuccessful  
104 transition and transfer?

105 What did you observe about the patient's family that may have contributed to an unsuccessful  
106 transition and transfer?

107 Were there any milestones that were missed that contributed to the failure to successfully  
108 transition and subsequent transfer? These milestones could be specific to the patient, family, or  
109 providers.

110 When and how did you suspect that the transition was on a trajectory toward being  
111 unsuccessful? For example, were there indicators made it clear that the transition was  
112 unsuccessful? What were they?

113 *Summarize their response.* To summarize that, I've heard you say that your patient had an  
114 unsuccessful transition as evidenced by \_\_\_\_\_. The key factors that contributed to  
115 their failure were \_\_\_\_\_. What other measurable outcomes might define an  
116 unsuccessful transition process for patients with <<condition>>?

## 117 **VI. Synthesis of responses into SMART**

118 Thanks for sharing those stories. I'd like your help in categorizing the factors you feel  
119 contributed most to the successes and failures of these patients during the transition process.  
120 We will use the Socio-ecological Model of AYA Readiness for Transition, also known as  
121 "SMART," to conceptualize transition readiness. SMART was developed at CHOP by Lisa  
122 Schwartz, a pediatric psychologist in oncology, and Lisa Tuchman, a former attending in  
123 adolescent medicine. *Explain SMART via the figure and review the various components.*  
124 *Emphasize the reciprocal nature of the model and the influence of many components.*

125 Let's take a look at the figure of SMART (*in person, or electronically for phone interviews*). The  
126 model conceptualizes the influence of pre-existing objective factors as well as the modifiable  
127 subjective factors of 3 groups: patients, parents, and providers. These 3 groups have reciprocal  
128 relationships as they are part of a system and have equal influence on the outcomes of the

129 transition. The modifiable subjective variables serve as potential targets of interventions  
130 implemented within clinical settings to improve the transition process.

131 I'll first review the pre-existing objective factors that may be less amenable to intervention in a  
132 clinical setting and that influence the rest of the transition readiness process. These include:

- 133 • Socio-demographics/Culture
- 134 • Healthcare Access or Insurance
- 135 • Medical status or risk
- 136 • Neurocognition/IQ

137 OK, next I'll review the modifiable subjective factors that are more amenable to interventions in  
138 a clinical setting and serve as potential targets of interventions to improve the transition  
139 process. Again, these can be specific to the patient, parent, or provider. These include:

- 140 • Knowledge
- 141 • Self-Management skills/Self-efficacy
- 142 • Beliefs/Expectations *(may need to clarify this is NOT spiritual beliefs but medical beliefs)*
- 143 • Goals/Motivation
- 144 • Relationships/Communication
- 145 • Psychosocial Functioning/Emotions

146 Finally, there is one additional modifiable factor which is specific to the patient. This is  
147 developmental maturity.

148 Do you have any questions about this model?

149 *Have definitions of each of the above available in case the interviewee has questions.*

## 150 VII. **Recommendations for app**

151 As I mentioned in the beginning, our research team is developing a smartphone app to be used  
152 by AYA with the goal of improving the transition process, and reducing adverse medical  
153 consequences that may follow unsuccessful transition to adult care. Taking into consideration  
154 the stories you just shared about successful and unsuccessful transitions, and the components  
155 we discussed from the SMART model, what aspects of transition do you think could be targeted  
156 and improved using a smartphone app? *Keep SMART model out for them to review.*

157 *Extensively probe based on response, encourage creativity, innovative ideas, and “thinking*  
158 *outside the box.”Focus more on the aspects of transition to target than on the actual technical*  
159 *implementation of an app here. Use the SMART model as a basis for this.*

160 *If they say “I have no idea,” say “Let’s start from the beginning. In order to prevent an adverse*  
161 *medical outcome from <<condition>>, such as <<outcome>>, which modifiable factors are most*  
162 *important to target? Now, thinking about the current capabilities of a smartphone, how might*  
163 *you target these factors with an app intervention?”*

164 *If they are completely stuck, give examples of intervention categories, such as text reminders,*  
165 *video content, games, social networking, communication with care providers.*

166 *Just a reminder, the app is only targeted to the adolescent patients. While the patient, parents,*  
167 *and providers have equal influence on the outcome, we will only be able to target the patient*  
168 *with the app.*

169 Great.

## 170 **VIII. Conclusion**

171 Thank you for taking the time to be interviewed today. Do you have any other thoughts or  
172 suggestions for the app we are developing?

173 Was there something you thought of during our time today that you didn’t have a chance to  
174 talk about?

175 If you think of anything else afterward that you forgot to mention, feel free to contact me using  
176 the email address we used to schedule this interview.

177 What other experts should we interview about this topic? It’s OK if they are from other  
178 institutions. *(Ask for names and email addresses if they have them and whether it is ok to*  
179 *reference the interviewee who made the recommendation in the email invitation.)*

180 Great, thank you again for your time.