

Supplemental Materials

Table 1. Parent/Caregiver Interview Guide

COM-B Domain	Questions
Introduction	<p>Thank you for agreeing to take part in our interview about your child's experience of transition and transfer from pediatric to adult care.</p> <p>We think of transition as the process of a child learning how to manage their health care on their own, preparing to transfer and becoming comfortable as a patient in adult care. Transition can start as soon as a child becomes a pediatric patient and lasts all the way until they are settled in to adult care. It is a gradual process where a child, the family and their health care providers work together to prepare the child for adulthood. Transition can include things like a child learning to take their medications on their own, and being able to talk to their health care providers without support from a parent or caregiver.</p> <p>We will also talk about transfer to adult care. Transfer is the point at which the IWK Health Centre transfers a child's care to a primary care provider (a family physician or nurse practitioner) or to a specialist in adult care.</p> <p>We are doing this research because transition and transfer can be very difficult for some youth and can lead to poor health outcomes, being lost in the adult health system, and having challenges in other areas of their life.</p> <p>Our goal is to better understand what makes for a successful transition to adult care, what helps make transition easier and what makes it more challenging from the perspectives of patients, parents/caregivers, and health care providers in Nova Scotia. What we learn from this study will be shared with the Transition of Care Committee, IWK Health Centre, Nova Scotia Health, the Department of Health and Wellness as well as with patients and families. The research team will work closely with the Transition of Care Committee (TOCC) at the IWK Health Centre and other stakeholder groups to determine what the most appropriate ways to deliver the findings to patients, parents/caregivers and health care providers.</p> <p>The information will help us to create interventions that will improve the transition to adult care.</p>
Opening question	<p>1) Let's start the discussion by talking about your son or daughter's experience of transitioning from pediatric to adult care. What was their experience like?</p> <p><i>(Prompt: How old was your son or daughter when they were first diagnosed with the condition/illness?)</i></p>
CAPABILITY	
Psychological & Physical Capability	<p>2) When did you start thinking about your child's need to transition from pediatric care to adult care? Did something prompt you to start thinking about it?</p> <p>3) How did you support your son or daughter to prepare for the transition?</p> <p><i>(Prompt: Receive any information or resources participate in any events, and develop new skills?)</i></p> <p>4) Was your personal knowledge and experience of the adult care system useful in supporting your son or daughter learn to navigate that new system – if so how?</p> <p>5) What do you think parents/caregivers need to know in order to support a smooth transition for their child? Did you have to learn anything new as a parent/caregiver?</p>

	<p><i>(Prompt: What kinds of practical information would you have liked your son/daughter to have to facilitate a smooth transition to function well in the adult system?)</i></p>
OPPORTUNITY	
Physical Opportunity	<p>6) From your experience, how does the process of accessing health care providers (HCP) in the adult health care system compare to the pediatric system? <i>(Prompt: Is the adult health care system different, or the same, as the pediatric system?)</i></p> <p>7) What challenges has your son or daughter encountered accessing their health care provider? What factors makes it easier for them to access their HCP?</p> <p>8) What type of tools, resources or programs did either you or your child used to help with their condition/illness when transitioning to adult care? Please explain.</p> <p>9) Were there situations during the transition that you could have used additional support with? If so, what?</p>
Social Opportunity	<p>10) How does your son or daughter prefer to connect or contact their health care provider? What would be the ideal way for them to connect with their HCP? <i>(Prompt: On ease of accessing information)</i></p> <p>11) Who would you say are the people that matter most to your child with helping them manage their condition/illness and symptoms? How do they help? <i>(Prompt: Parents, friends, other people with same condition)</i></p>
MOTIVATION	
Automatic Motivation	<p>12) Did you have any apprehensions when you thought about your child's transition to adult care? What factors went into those concerns?</p> <p>13) What do you consider a successful transition? How do you define a successful transition?</p> <p>14) Were you motivated to aim for a successful transition? If so, what factors have motivated you? Was there a particular event or experience that motivated you?</p>
Reflective Motivation	<p>15) How confident did you feel in your child's ability to transition from pediatric to adult care? <i>(Prompt: What goals did you in relation to your son or daughter's transition from pediatric to adult care?)</i></p> <p>16) What responsibilities did you have as a caregiver to ensure your child's transition from pediatric to adult care was successful? What was your role?</p>

	<p>17) What were your child's responsibilities to ensure the transition was successful? What were the health care providers' responsibilities?</p> <p>18) Do you believe there is sufficient support to transition from pediatric to adult care? Please expand.</p>
OTHER	
Not COM-B Domains	<p>19) What advice would you give other children and parents/caregivers going through a transition from pediatric to adult care? <i>(Prompt: Expectations versus Reality?)</i></p> <p>20) Is there anything else that you would like to add?</p> <p>21) How would you like these findings to be shared?</p>

Table 2. Youth Interview Guide

COM-B Domain	Questions
Introduction	<p>Thank you for agreeing to take part in our focus group about your experience of transition and transfer from pediatric to adult care.</p> <p>We think of transition as the process of learning how to manage your health care on your own, preparing to transfer and becoming comfortable as a patient in adult care. Transition can start as soon as you become a pediatric patient and lasts all the way until you are settled in to adult care. It is a gradual process where you, your family and your health care providers work together to prepare for you for adulthood. Transition can include things like learning to take your medications on your own, and being able to talk to your health care providers without support from your parent or caregiver.</p> <p>We will also talk about transfer to adult care. Transfer is the point at which the IWK Health Centre transfers your care to a primary care provider (a family physician or nurse practitioner) or to a specialist in adult care.</p> <p>We are doing this research because transition and transfer can be very difficult for some youth and can lead to poor health outcomes, being lost in the adult health system, and having challenges in other areas of their life.</p> <p>Our goal is to better understand what makes for a successful transition to adult care, what helps make transition easier and what makes it more challenging from the perspectives of patients, parents/caregivers, and health care providers in Nova Scotia. What we learn from this study will be shared with the Transition of Care Committee, IWK Health Centre, Nova Scotia Health, the Department of Health and Wellness as well as with patients and families. The research team will work closely with the Transition of Care Committee (TOCC) at the IWK Health Centre and other stakeholder groups to determine what the most appropriate ways to deliver the findings to patients, parents/caregivers and health care providers.</p> <p>The information will help us to create interventions that will improve the transition to adult care.</p>
Opening question	<p>1) Let's start the discussion by talking about your experience (or experiences) of transitioning from pediatric to adult care. What was your experience like? <i>(Prompt: How old were you when you were first diagnosed with condition/illness?)</i></p>
CAPABILITY	
Psychological & Physical Capability	<p>2) When did you start thinking about the need to transition from pediatric care to adult care?</p> <p>3) What did you know about the adult health care system? <i>(Prompt: how did you learn about the adult health care system?)</i></p> <p>4) (might be answered with question above) What do you think you need to know or prepare in order to have a smooth transition? Did you have to learn anything new? Did you research or look up anything beforehand? If so, what type of information? <i>(Prompt: information about your diagnosis, medications, how to make an appointment)</i></p> <p>5) When do you think self-management skills for transition should be taught?</p>
OPPORTUNITY	

Physical Opportunity	<p>6) How do you access your health care providers (HCP) in the adult health care system? Could you describe this process? <i>(Prompt: What happens in the event of an emergency? How do you access emergency care?)</i></p> <p>7) How is the adult health care system the same or different than the pediatric system?</p> <p>8) What challenges have you encountered with accessing your health care provider in the adult healthcare system? What makes it easier to access your HCP?</p> <p>9) What type of tools, resources or programs (if any) helped you with your condition/illness when transitioning to adult care? Please explain.</p> <p>10) Were there situations during the transition that you could have used additional support with? If so, what? <i>(Prompt: Do you have any ideas for new tools and programs or ways to improve existing resources that could have helped transition to adult care? If so, what?)</i></p>
Social Opportunity	<p>11) How do you like to connect or contact your health care provider? What would be the ideal way to connect with your HCP? <i>(Prompt: Was it easy to access information? Did you know who you are transitioning to?)</i></p> <p>12) When you were mid-transition, who did you contact when you have a question or concern?</p> <p>13) Do you feel comfortable talking to your HCP? Do you feel like you can trust them? Do you understand what they are explaining to you? Please explain.</p> <p>14) Who impacted your experience when transitioning from pediatric to adult care? How did they impact you? <i>(Prompt: Who? parents, guardian, health care provider friends, other people with same condition; How did they help manage your experience transitioning?)</i></p> <p>15) <i>(If they mention parents)</i> What was the role of parents throughout the transition?</p> <p>16) Was there sufficient support to transition from pediatric to adult care? Please expand. <i>Was it a partnership? Was it rushed or did you feel you were pushed to things before you were ready, etc.</i></p>
MOTIVATION	
Automatic Motivation	<p>17) How did you feel in preparation for your transition? Did you feel worried, concerned, empowered, and/or excited?</p> <p>18) What factors motivated you throughout the process of transitioning from the pediatric to adult health care system? <i>(Prompts: incentives, rewards, goals, a specific event?)</i></p> <p>19) When did you want to start talking about transition? When do you think it is too early/when is too late?</p>
Reflective Motivation	<p>20) How confident did you feel in your ability to transition from pediatric to adult care? <i>(Prompt: Did you feel ready? What thing did you want to achieve related to the transition from pediatric to adult care? (i.e., goals?)</i></p>

	<p>21) What responsibilities did you have as a young adult to ensure the transition from pediatric to adult care is smooth?</p> <p>22) Overall, what would you consider a “good” transition to look like? <i>(Prompt: When would you consider a transition to end?)</i></p>
OTHER	
Not COM-B Domains	<p>23) What advice would you give others going through a transition from pediatric to adult care? <i>(Prompt: expectations versus reality?)</i></p> <p>24) Is there anything else that you would like to add?</p> <p>25) How would you like these findings to be shared?</p> <p>Leave 15 minutes at the end for open discussion</p>