

Supplementary File 2: Study Measures

Data Collection Forms	Completed by	Timing		
		Screen Prior to Baseline	Baseline Visit	6 Month Visit
Primary Outcome Measure				
<p><i>Transition Readiness Assessment Questionnaire (TRAQ)</i> [1]</p> <p>The TRAQ has often been used in previous studies to measure transition readiness [2]. While TRAQ measure refinement is ongoing, and other versions are now available, our sample size calculation is based on findings from an intervention trial [3] where the 29-item version of the TRAQ was used. The 29-item version has a Self-management domain (16 items) and a Self-advocacy domain (13 items). Each item is scored from 1-5, where 1 = “I do not need to do this”, 2 = “I do not know how but I want to learn”, 3 = “I am learning to do this”, 4 = “I have started doing this”, and 5 = “I always do this when I need to”The TRAQ will be completed by youth participants in both groups at Baseline and at 6-Months.</p>	Youth		X	X
Secondary Outcome Measures				
<p><i>TRANSITION-Q</i> [4]</p> <p>The TRANSITION-Q is a 14-item transition readiness/self-management ability scale [4,5]. This short, clinically meaningful and psychometrically sound scale can be used in research and in pediatric and adolescent clinics to help evaluate readiness for transition [4]. Item responses (“never” = 0, “sometimes” = 1, and “always” = 2) are summed to create a raw score, with a possible range from 0 to 28. Raw scores are transformed using a table provided by the developers and the transformed scores range from 0-100. A higher score indicates greater transition readiness; exhibiting more self-management skills with higher frequency [4,6].</p>	Research Assistant with youth	X		X
<p><i>Canadian Occupational Performance Measure (COPM)</i> [7]</p> <p>The COPM is an evidence-based, generic, and individualized outcome measure used to capture a client’s self-perception of performance and satisfaction in everyday living, over time [7]. The measure can be used to identify problems in</p>	Research Assistant with youth		X	X

performing activities of daily living, and the participant is encouraged to think about things that they want to do, need to do or are expected to do but can't do, don't do or aren't satisfied with the way they do. The participant will be asked to rate the current performance of each using a 10-point scale from 'not able to do it' to 'able to do it very well'. The patient is also asked to rate satisfaction with performance on a 10-point scale from 'not satisfied at all' to 'extremely satisfied' with higher scores reflecting better performance and satisfaction with performance as perceived by the participant. The performance and satisfaction can be re-assessed following a period of treatment [8].				
<i>Newest Vital Sign</i> [9] The NVS is a health literacy measure that can be easily administered in three minutes. The NVS will help provide a description about participants at baseline and explore determinants of change in self-management, as well as tailoring the intervention in the knowledge translation phase.	Research Assistant with youth		X	
<i>PedsQL™ Pediatric Quality of Life Instrument, Generic Core, Teen Report (13-18 years)</i> [10] The PedsQL™ Pediatric Quality of Life Instrument, Generic Core, Teen Report (13-18 years) will be completed by youth participants at Baseline and at 6 months. The form is brief (23 items), practical (less than 4 minutes to complete), multidimensional (physical, emotional, social, school functioning), reliable (child self-report; 0.90) and valid (distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition), and responsive to clinical change over time.	Youth		X	X
<i>System Usability Scale (SUS)</i> [11] is a self-reported survey focusing on users' utilization of the application and its features, the perceived value, experience and satisfaction with the intervention. It will provide additional information about the users' adherence, behavior, motivation and experience with the IT platform, as well as the main reasons for using or not using it.	Youth (intervention group)			X
<i>Demographic Information Form</i> was developed by the CHILD-BRIGHT Network. Studies involving humans collect information on gender, race and ethnicity as well as other characteristics of individuals that may influence how people respond.	Parent		X	

These questions will help us understand and describe the participants in CHILD-BRIGHT studies.				
<i>Profile Information Form</i> was developed by the CHILD-BRIGHT Network and includes questions about the child's functionalities and how certain factors might impact their quality of life. These questions will help us understand and describe the participants in CHILD-BRIGHT studies.	Parent		X	
<i>Measure of Process of Care (MPOC)</i> [12] The Measure of Processes of Care is a well-validated and reliable self-report measure of parents' perceptions of the extent to which the health services they and their child(ren) receive are family-centred. The original version of MPOC is a 56-item questionnaire; as of 1999 there is a shorter, 20-item version. MPOC has been used internationally in many evaluations of family-centred service. Parents/caregivers will complete the (modified with permission) MPOC-20 at Baseline and 6-Months.	Parent		X	X
<i>Health Utilities Index® (Hui2/3) Proxy-Assessed (health-related quality of life)</i> [13] The HUI is a generic health status instrument developed in Canada for use with children and has been incorporated in numerous clinical studies as well as the Canadian Community Health Survey, allowing the generation of norms for most age groups.	Parent		X	X
<i>Resource Use Questionnaire (RUQ)</i> [14] The RUQ is typically an interviewer-administered questionnaire for parents of children aged 11 to 18 years. The original RUQ measures the family resource use of condition-related treatments, services and programs, as well as parent time losses and family out-of-pocket costs. It also documents condition-related government subsidies and funding that families receive. Resources measured include those delivered by a parent, by other providers (e.g. behavioural specialist) or a combination of both. In this RCT, a modified subset of RUQ questions will be administered and completed by the parent/caregiver.	Parent		X	X

References

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