

OCHSU/HAHSO Transition Stakeholder Alliance Meeting
June 2 2017
Meeting Objectives and Summary Notes

Meeting Objectives:

1. To review results of the OCHSU study with an in-depth look at the psychometric validation of the Transition-Q
2. To provide an introduction to the MyTransition App and discuss its application and various components
3. To discuss the current HAHSO funded pilot RCT study and long term plans in transition research with a focus on strengthening stakeholder alliance

Morning Presentation Summary:

In the morning session of the meeting, Dr. Jan Willem Gorter presented on the OCHSU funded *Teens Reaching Adulthood: Needs and Support for Improved Transitional care In Ontario (TRANSITION)* study's development, methods and results. Dr. Anne Klassen spoke regarding the further psychometric validation of the Transition-Q, the study's intervention. During the discussion following the presentations, attendees had the opportunity to discuss the Transition-Q. The main points mentioned were the importance of measurement scales that resonated with patients, the potential of the Transition-Q's immediate feedback as a snapshot of the patient's transition state and a springboard for goal-setting conversation, and the question of how to standardize and account for varying readiness levels for different chronic conditions. A parental and healthcare professional version of the Transition-Q was proposed, which could offer additional perspectives on the youth's transition readiness. Many participants also suggested removing the score generated by the Transition-Q, and placing a larger focus on the 'always,' 'sometimes,' 'never' response options of the questionnaire.

Interactive Breakout Session Summary:

After morning break, attendees were placed in groups and moved from table to table to discuss various aspects of the MyTransition App.

General Comments: The table discussed the benefits of the app to include empowering the patient and facilitating independence, helping change clinic visits to incorporate more transition conversations, and setting a foundation for future planning. Participants recommended that healthcare providers prescribe the app, a handy tool available on phones, when the child turns 14, and begin using the app during every clinic visit. It was suggested that adult healthcare providers would also benefit from its use to prevent an overload of information towards the end of transition. Participants brainstormed strategies for building awareness of the app, including through youth advisory committees, social media, and posters in clinics.

3 Sentence Summary: The table listed various benefits, including helping healthcare providers better understand their patients' areas of need, and helping patients become better versed in

their condition to increase their confidence and communication ability, which in turn encourages patients to take charge of their own health. Many thought it is great tool for all ages, and is useful to complete before new appointments with adult healthcare providers, especially if the medical condition or history is complex. Some design and content suggestions included having an auditory component, larger font, and a fourth statement for the healthcare provider to write recommendations.

Transition-Q: Another table discussed the Transition-Q, and deemed it a helpful tool to track progress overtime, and identify goals to work on with guidance from the healthcare provider. It was suggested that youth aged 17-24 would benefit most from this measure. By completing the Transition-Q before entering a transition program, it could help healthcare providers tailor interventions, and compare levels of transition readiness among patients. Participants thought the measure should be completed in the clinic multiple times instead of just once, and results could be incorporated in the patient's chart. Some recommendations participants provided include making design modifications to increase user-friendliness, eliminating the numerical score, adding suggestions for goal-setting, and flagging unreachable goals in order for providers and parents to adjust accordingly.

MyHealth Passport: Those discussing the MyHealth Passport thought the tool would benefit school-aged kids, nonverbal patients, and those pursuing a post-secondary education, but not patients with a vague diagnosis or multiple conditions. It contains a quick summary of a patient's medical information, and thus participants thought it would be useful when communicating one's medical history, especially during a medical emergency. It was mentioned that the youth should complete the form with support from the clinician during transition and at transfer, and print a copy of the summary sheet to have with them. Suggestions included allowing addition of immunization history, allowing the form to save new edits to the health information, and implementing the tool in waiting rooms to allow youth to fill it out before their appointments.

Overall Feedback: The last table discussed overall feedback for the MyTransition App. Participants approved of the app's simple and user-friendly design, but recommend various changes to align with accessibility standards. Other suggestions included building in a rewards system, syncing it to one's electronic health record, and adding a calendar function, a homepage, reminder functions, and links to other helpful resources. There was a general consensus that youth would not be motivated to utilize the app on their own accord; instead, it would be more effective to implement this app in the practice of healthcare providers.

Afternoon Presentation Summary:

In the afternoon session, Dr. Gorter and Nadlein Mahlberg presented on the HAHSO funded *An app-based Transition Toolkit targeting youth with chronic health conditions: A randomized control trial as a foundation to improve healthcare transitions and outcomes (ApplyIT)* study and its planned future expansion into a multi-centre randomized control trial, to assess the implementation of the MyTransition App. The discussion following the presentation focused on

suggestions for the study, including identifying a method to track frequency of app use, and revising the inclusion criteria to clarify what population is defined as 'independent.' Questions posed include: at what age youth would be able to use the app, whether reminders to use the app would be effective, and whether healthcare providers have the time and resources to address each patient's app results. The issue of how to address the population with lower cognitive skills or those that may never transition completely was also considered.

Dr. Gorter wrapped up the meeting with a presentation of *CanChild's* long-term plans on transition research, and expressed a wish to establish a strong stakeholder alliance. The group noticed a lack of adult healthcare provider participation in transition research, and brainstormed strategies for their engagement, such as promoting transition through personal connections, sending out invitations to medical divisions to identify interested adult healthcare professionals, and increasing general awareness of the issues surrounding transition. Moreover, a need for greater involvement of individuals in health policy and systems planning was recognized, with attendees recommending more engagement at the LHIN level. Regarding youth and families, an emphasis was placed on early intervention, the importance of developing resources for youth who may never be able to self-manage, and the potential use of technology for greater engagement (e.g. monthly webinars in addition to in-person meetings). The meeting concluded on a positive note that individuals all over the world today are able to get involved in the conversation around transition.