What matters to you(th) preparing for adult healthcare in Canada: A mixed-methods approach to improving readiness assessments

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Background

- > At 16-19 years of age, adolescents and young adults (AYA) with chronic medical conditions must transition from their pediatric specialist to an adult specialist. AYA often feel **unprepared** for this transition which making transition preparations crucial.
- > Transition preparations can be guided by initial scores on transition readiness assessments. The Transition Readiness Assessment Questionnaire (TRAQ) is the most validated and cited readiness measurement. While the TRAQ is highly cited and implemented, it was developed with minimal patient involvement.
- > The lack of patient engagement in the design, development, and validation of readiness assessments makes it difficult to identify which transition behaviours to measure, as the perspective and priority of AYA may differ from that of clinicians and researchers.

Research Objective

> We aim to validate the TRAQ and provide evidence for future studies to include codesign principles in the development of transition readiness assessments.

Significance

- > This work will create a better understanding of the effectiveness of TRAQ in determining transition readiness over time. Using patient navigator notes will be a novel approach to understanding transition behaviours that will glean a more fulsome insight into the transition experience.
- \succ As this study is guided by patient engagement, the results of our partnerships will provide insights into student-patient partnerships within an MSc thesis.

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- > Sex, gender, ethnicity, immigration, socioeconomic status, mobility, and language spoken at home can influence healthcare transition readiness and transition experiences.
- > Qualitative and quantitative methods will be used to investigate how these contribute to different experiences related to transition preparation and transition outcomes.

Methods

 \succ In partnership with the TRAC, this study will use a patient-oriented approach to ensure youth-friendliness and relevance of the research questions and findings. TRAC has previously advised on multiple projects informing study designs.

Sequential-Explanatory Mixed Methods Design

Quantitative: Perform Generalized Estimating Equation to examine the extent of TRAQ score correlation for each participant at three time points.

Qualitative: Analyze Patient Navigator case notes to explore what transition behaviours were observed and reported.

Integration: Explore what transition behaviours are being measured and what is being observed and where the qualitative and quantitative data are aligned or not.

Knowledge Translation: Co-design youth-friendly knowledge translation outputs for traditional academic and non-traditional channels.



Transition 15 youth and siblings (aged 16-Research Advisory 35) with lived experiences in health/mental health systems Council (TRAC) Phase 2: Qualitative Phase 3: Integration Joint displays to report a summary of Patient Navigator notes at regularly total and subscale TRAQ scores and scheduled meetings. results from the analysis of case notes. Co-development of joint displays and Theme development/refinement interpretation of results interpretation

Phase 1: Quantitative TRAQ data at 0,12,24 months. TRAC members assist with analysis and

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Addressing the patient engagement gap in transition readiness assessments is critical to improving their effectiveness and relevance to aid in successful transitions to adult care minimizing adverse outcomes.

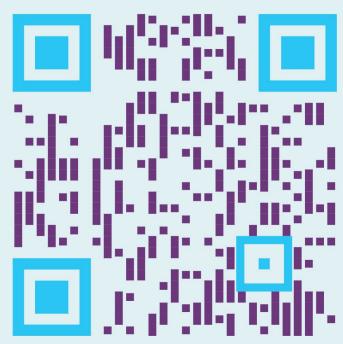
> Contributed to recruitment strategies, identifying gaps in care, developing questionaries, & ensuring youth-friendliness on research materials contributing to important and nuanced considerations for researchers.

Co-development of future directions

Phase 4: Knowledge Translation

Co-designed materials for all relevant end-users.

Co-presentations, co-authorship, development of social media content.



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