

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 co-design 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.
- As this study is guided by patient engagement, the results of our partnerships will provide insights into student-patient partnerships within an MSc thesis.

EDI/SABA

- 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

- 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.



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.

Transition Research Advisory Council (TRAC)

15 youth and siblings (aged 16-35) with lived experiences in health/mental health systems

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

Phase 1: Quantitative

TRAQ data at 0,12,24 months.

TRAC members assist with analysis and interpretation

Phase 2: Qualitative

Patient Navigator notes at regularly scheduled meetings.

Theme development/refinement

Phase 3: Integration

Joint displays to report a summary of total and subscale TRAQ scores and results from the analysis of case notes.

Co-development of joint displays and interpretation of results

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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