

Collaborating with patient partners to plan and conduct a stakeholder dialogue about Canadian transition practices and policies related to age of transfer to adult healthcare

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on behalf of the CHILD-BRIGHT READYorNot™ Brain-Based Disabilities Project Team

Co-Presented by Claire Dawe-McCord (Medical Student and Young Adult Partner), Linda Nguyen (Postdoctoral Fellow), and Michael Frost (Young Adult Partner)

Background

- The transition to adulthood includes many psychosocial changes that can present challenges for all youth, but especially for a growing number of youth with chronic conditions who are preparing for the transition from pediatric to adult healthcare [1].
- Our review of legislation in Canada identified a lack of transition policies, and that transition practices and guidelines varied between provinces and providers.

Purpose

- To understand the perspectives of stakeholders about policies on transition from pediatric to adult healthcare in Canada.
- To identify what is missing in current healthcare transition policies.
- To provide recommendations about future policy changes to support healthcare transition.

Methods

- A stakeholder dialogue was planned and co-facilitated by the CHILD-BRIGHT's READYorNot™ Brain-Based Disabilities Project, a subgroup of young adult members of the Patient and Family Advisory Council (PFAC) in collaboration with the CHILD-BRIGHT Policy Hub.

References

[1] Yeo M, Sawyer S. Chronic illness and disability. BMJ. 2005;330(7493):721-723. doi:10.1136/bmj.330.7493.721
[2] Gorter JW, Amaria K, Kovacs A, et al. CHILD-BRIGHT READYorNot Brain-Based Disabilities Trial: protocol of a randomised controlled trial (RCT) investigating the effectiveness of a patient-facing e-health intervention designed to enhance healthcare transition readiness in youth. BMJ Open. 2021;11(3):e048756. doi:10.1136/bmjopen-2021-048756

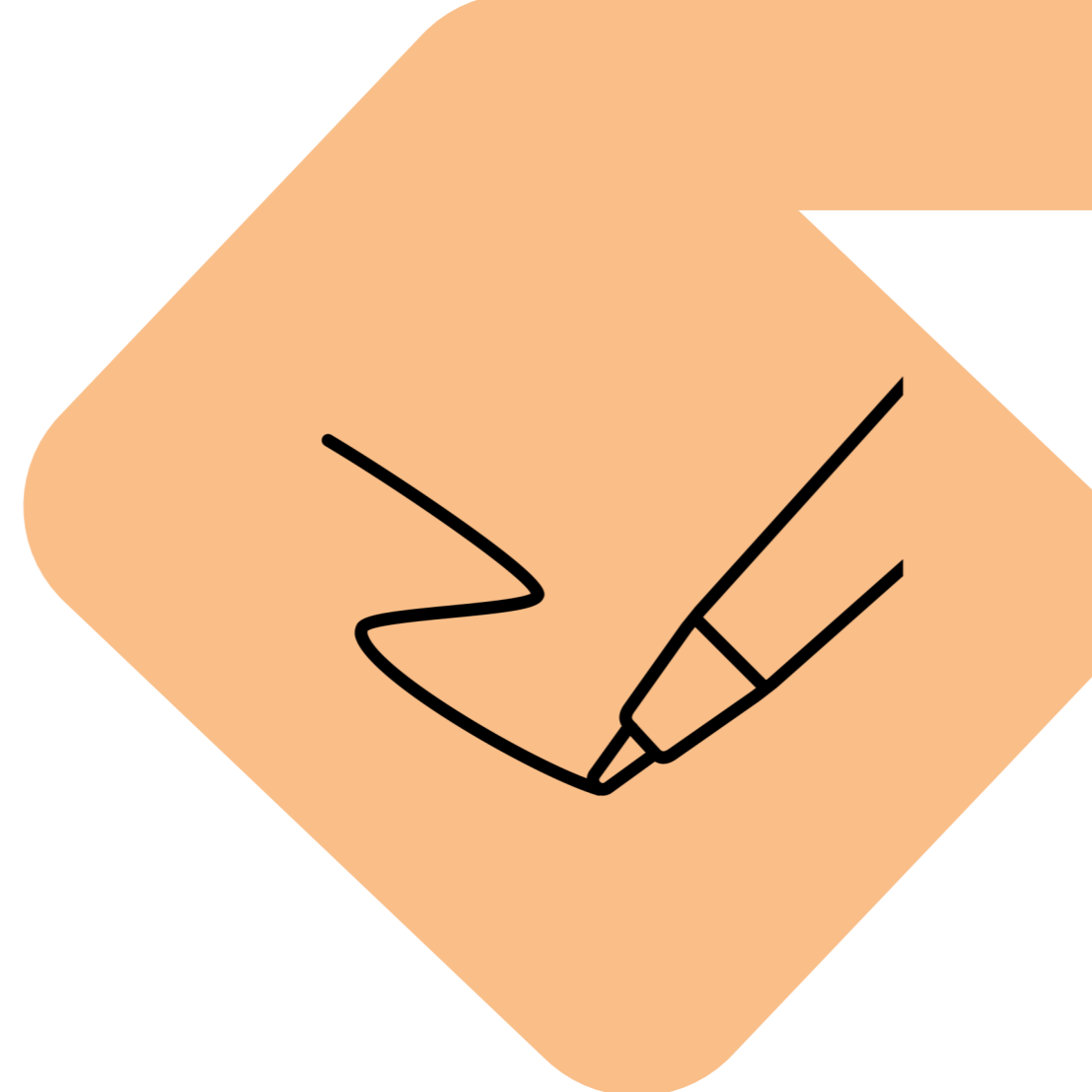
Process of Our Collaboration

Literature Review



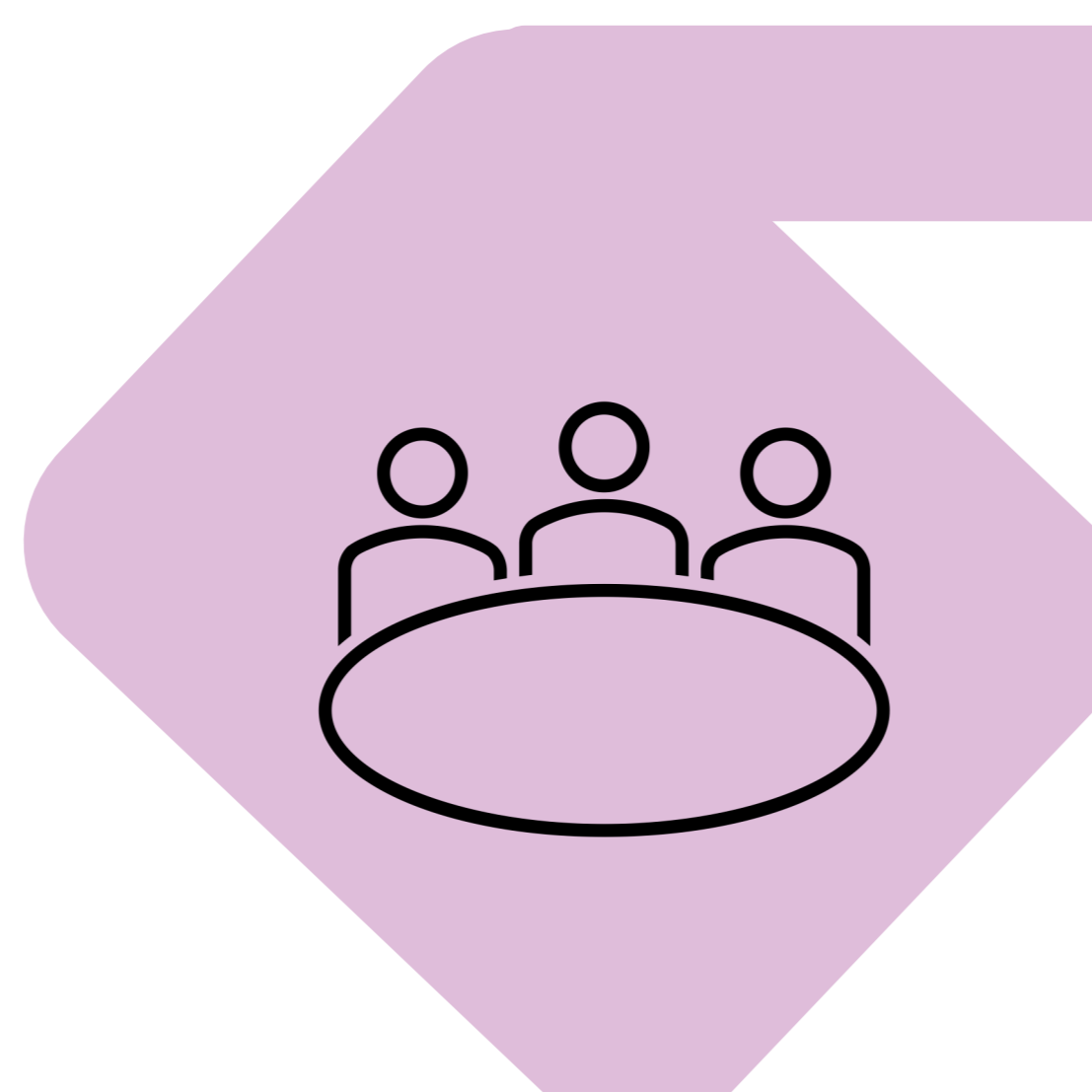
- ✓ Young adult partner (Claire Dawe-McCord) reached out to experts in the field of transition.
- ✓ Discussed with PFAC about priorities.
- ✓ Performed informal review of existing transition legislations.

Development of Patient Vignettes



- ✓ Selected the use of vignettes with prompting questions to encourage discussion among stakeholders.
- ✓ The PFAC shared relevant and real-life examples to inform the co-development of two vignettes of youth preparing to transfer to adult care ([Vignette 1](#), [Vignette 2](#)).
- ✓ Identified stakeholders to invite.

Stakeholder Dialogue and Analysis



- ✓ Dialogue was held on February 1st, 2022.
- ✓ The PFAC provided significant input in the planning and organization of the event, e.g., suggesting a Google Jamboard as a way for stakeholders to provide feedback and including closed captioning in the vignette videos.
- ✓ Analyzed dialogue transcripts and drafted policy brief.

"I think the most valuable aspect is that when I provided all of my experiences, it was to multiple stakeholders. And I believed it provided added value in the decision-making."
- Musa Arafah (Young Adult Partner and Event Co-Host)

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<https://www.child-bright.ca/readyornot>



Results To Date

Nine participants, including three youth, one family partner, two researchers, and three healthcare workers, from Ontario, Quebec, Alberta, New Brunswick, and Nova Scotia.

Stakeholders spoke about inconsistent practices and lack of adherence to the practices that did exist, as well as a lack of training and resources for healthcare professionals to support transition.

Top 3 Policy Recommendations

- 1 A planning program for the transfer from pediatric to adult healthcare services that starts a few years before the transfer and builds self-competencies.
- 2 A more flexible age of transfer since chronological age does not necessarily indicate developmental age or readiness.
- 3 Holistic transition that includes social and educational factors.

Next Steps

Currently, we are finalizing the policy brief and dissemination plan.

Acknowledgements

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