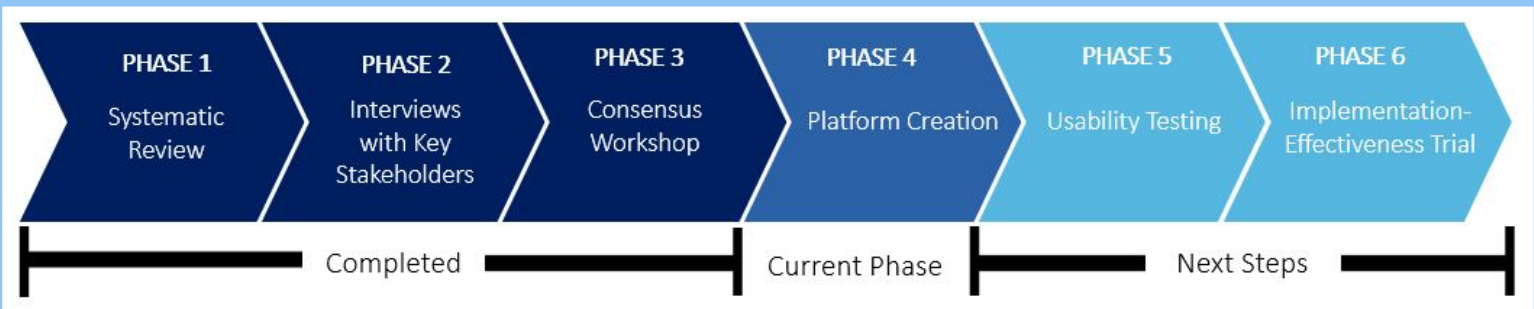


Measuring what Matters: Integrating Patient-Reported Outcomes into Clinical Practice

It's been a great year!



Research Program Timeline Integrating PROMs into Clinical Practice

Knowledge Translation & Dissemination

Findings from **Phase 1** were published in *Pediatric Transplantation*.

- Anthony SJ, Stinson H, Lazor T, Young K, Hundert A, Santana MJ, Stinson J, West L. *Patient-reported outcome measures within pediatric solid organ transplantation: A systematic review*. *Pediatric Transplantation*. 2019; 23(6):e13518.

Findings from **Phases 1 – 3** were shared at several national and international scientific meetings including:

The **2019 Canadian Transplant Summit** (Banff, Alberta) & the **International Society of Quality of Life 26th Annual Conference** (San Diego, California).

- “*Improving the Care for Pediatric Transplant Patients Through Integration of Patient-Reported Outcome Measures into Clinical Practice*”.

An invited national keynote presentation at the **Canadian Society of Transplantation (CST) Pediatric Group Annual General Meeting** – October 2019 (Banff, Alberta).

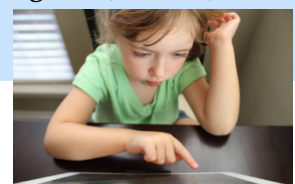
- “*Capturing the Patient’s Voice: Implementing Patient-Reported Outcome Measures into Clinical Practice in Pediatric Solid-Organ Transplantation*”.

An invited international keynote presentation at the **European Reference Network Transplant – Child, Board Meeting** – November 2019 (Padova, Italy).

- “*Capturing the Patient’s Voice: Integrating Patient Reported Outcome Measures into Clinical Practice*”.

Next Steps

- **Phase 4:** Development of the PROM platform will be led by the SickKids Centre for Computational Medicine and design/branding of the platform will be led by an external vendor.
- **Phase 5:** Patients and healthcare providers will be instrumental in the usability testing phase of the platform.
- Development of a national PROM steering committee comprised of key stakeholders in partnership with the Canadian Donation and Transplantation Research Program (CDTRP).



Phase 3: Workshop

25 participants including patients, caregivers, healthcare providers, researchers and administrators



Phase 3: Workshop, December 2018

Your feedback...

- “I found the workshop to be **engaging, informative, and productive**. As a patient, I was a bit nervous prior to the workshop about whether or not I would feel comfortable to share my input, but the environment and space that your team created eased my worries.”
- “It was refreshing for me to work with a group of people that really are **passionate** to get this going for pediatric transplant patients.”
- “Thank you for including the **patient’s voice!!!** I just wanted to say how impressed and encouraged I am by the work you are doing. It is such a **vital and necessary part of the continuum of care.**”



Funding for the Phase 3: Workshop was generously provided through the Canadian Institutes of Health Research Patient-Oriented Research Collaboration Grant

Project Funding Update

- Successfully obtained funding from the SickKids Transplant & Regenerative Medicine Centre Pilot Grant competition and the CDTRP 2018 Research Innovation Grant competition for the development of the PROM platform.
- Successfully obtained funding from Health Canada through the Health Care Policy Contribution Program for the development, usability testing and implementation of the PROMs platform in partnership with the CDTRP, CST and the Canadian Transplant Association.
- Initial implementation will occur at SickKids, with future national implementation to follow.



Health
Canada

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Introducing our electronic PROM platform Voxe!



More to come as we launch Voxe in the coming months

<https://www.getvoxe.com/>

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