Engaging patients with rare disease in quality improvement and research

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Introduction

Researchers and clinicians within the CHEO Regional Genetics Program recognize the critical importance of the patient voice in research and care, especially in the field of rare disease. At the same time, patients and families desire meaningful input into their care and rare disease research. Engaging patients and their families can be difficult: it may not be clear how healthcare providers, researchers and patients with diverse experience can connect with one another at the right time for input into research priorities, grant opportunities or decisions about how healthcare services are redesigned. The introduction of a continuous improvement system in the Genetics Program presented an opportunity to actively explore how to best develop patient and family engagement that is both meaningful and impactful.

Methods

Here we report on the experiences from our Canadian Institutes of Health Research-funded program of work that has sought to develop relationships and opportunities to engage patients, clinicians, and researchers in a dialogue about patient engagement as well as develop infrastructure and opportunities for meaningful engagement. A team of clinicians, researchers, and a patient co-investigator are collaborating to co-design a) a strategy for ongoing engagement with patients and families affected by rare diseases and b) 'touchpoints' in the quality improvement and research cycles where patient engagement can and should take place.

Half-day symposium

The team convened a multidisciplinary half-day to introduce existing, potential and future opportunities for patient engagement in Genetics. 43% of participants had not previously involved children, youth, or families as partners in a research or quality improvement project.

Situating ourselves in the patient engagement landscape

The local collaboration coincided with emergence of an institution-level patient engagement framework, adding complexity to the landscape and highlighting the imperative to clarify the ask of patient participants as well as local coordination to avoid duplication of effort and confusion potentially generated by parallel activities.

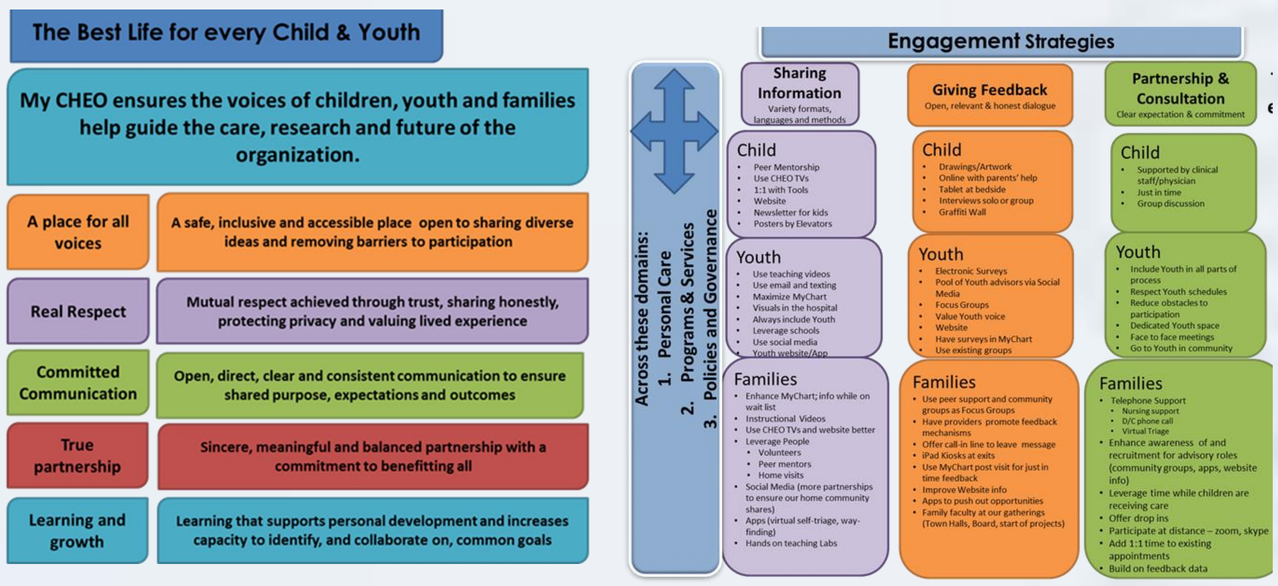

Figure 2. CHEO's guiding principles: what engagement would feel & look like at CHEO. Courtesy Kouri & Cunningham April 2018

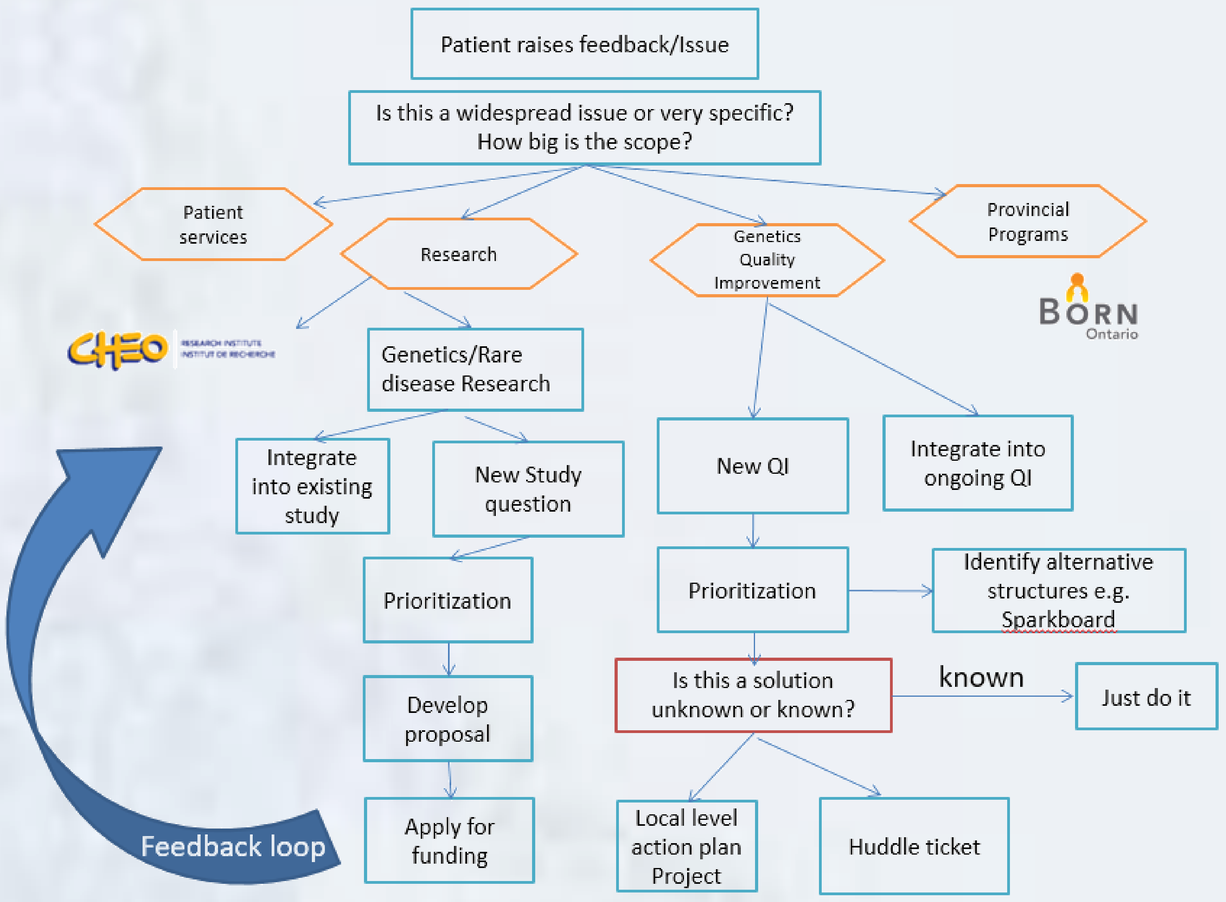

Figure 1. Touchpoints for patient engagement in the clinical genetics department

Barriers and facilitators identified:

Barrier: Time & compensation for diverse patients to participate. The notion of a patient perspective that could "represent" many unique and rare experiences is a barrier to engage with patients for some clinicians.

Facilitator: Patient engagement training for both researchers, clinicians and patients to empower involvement and recognize opportunities.

Facilitator: Face to face meetings to explore opportunities, build relationships, and identify priorities for future investigation

Barrier: Full partnership in research programs. We identified that patients are frequently not offered co-investigator status through research ethics applications due to the training and institutional requirements and the perception that it is unnecessarily cumbersome. Our patient partner chose to undertake Tri-Council Policy Statement 2 training and research portal training was therefore empowered to participate as a full co-investigator.

The institutional landscape for patient engagement is in flux which creates momentum and opportunities to participate, but can also be seen as a barrier in that it's difficult situate ourselves and avoid duplication of efforts, particularly with respect to recruitment and avoiding confusion with differing definitions of roles and responsibilities.

StrategyNext 2018-19
Our Action Plan

Next steps

We've learned that for collaborations to be successful, we need to be clear on the ask of patients, roles and responsibilities and time commitment. We've also heard that feedback on the outcomes of projects is important. Like any relationship, there needs to be communication (not too frequent, but avoiding long gaps). We hope to move forward with the following:

- Patient co-design of satisfaction indicators for the Genetics service
- Delphi to identify key QI and research Qs, alignment with strategic directions
- Design of recruitment strategy for ongoing feedback tailored to Genetics & Rare disease care at CHEO; potentially leveraging *Rareconnect* platform
- Integration of patient voice in local-level action planning planning process

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