

Strategies for Engaging Patients and Families as Equal Partners in Mental Health Research: A Focus on Improving Early Psychosis Intervention Care for Youth and Emerging Adults

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BACKGROUND

NAVIGATE is a recovery-oriented, manualized model of Early Psychosis Intervention (EPI) service that aims to improve youth and emerging adults suffering from a first episode of psychosis (FEP) by offering a **wrap-around model of care** in line with Ontario Ministry of Health's EPI standards. Our project is evaluating the implementation, fidelity, sustainability, and individual-level symptomatology and functioning outcomes for youth receiving NAVIGATE.

Within our project, we meaningfully engage patients and family members with lived experiences of FEP as equal research partners. According to **Canada's Strategy for Patient-Oriented Research (SPOR)**, involving patients and families in healthcare research ensures that studies focus on patient-identified priorities, ultimately leading to improved individual- and system-level outcomes.

SPOR's Guiding Principles

INCLUSIVENESS

Diverse lived experience perspectives are brought into the main research questions.

CO-BUILDING

Service users and researchers collaborate to set research priorities and produce solutions.

MUTUAL RESPECT

Folks with lived experience and researchers value one other's expertise and experiential knowledge.

SUPPORT

A safe environment is maintained to ensure folks with lived experiences can fully contribute to research discussions.

METHODS

At the start of our project, we formally established 2 committees:

Youth Advisory Committee
6 members

Youth between 14 and 35 years of age with lived experiences of FEP and are towards the end or have completed an Ontario-based EPI program.

Family Advisory Committee
8 members

Caregivers with a loved one between 14 and 35 years of age who are currently or previously been in an Ontario-based EPI program.

Each committee meets virtually once per month to guide recruitment strategies, assessment and treatment protocols, outcome measures, and the interpretation and dissemination of findings.

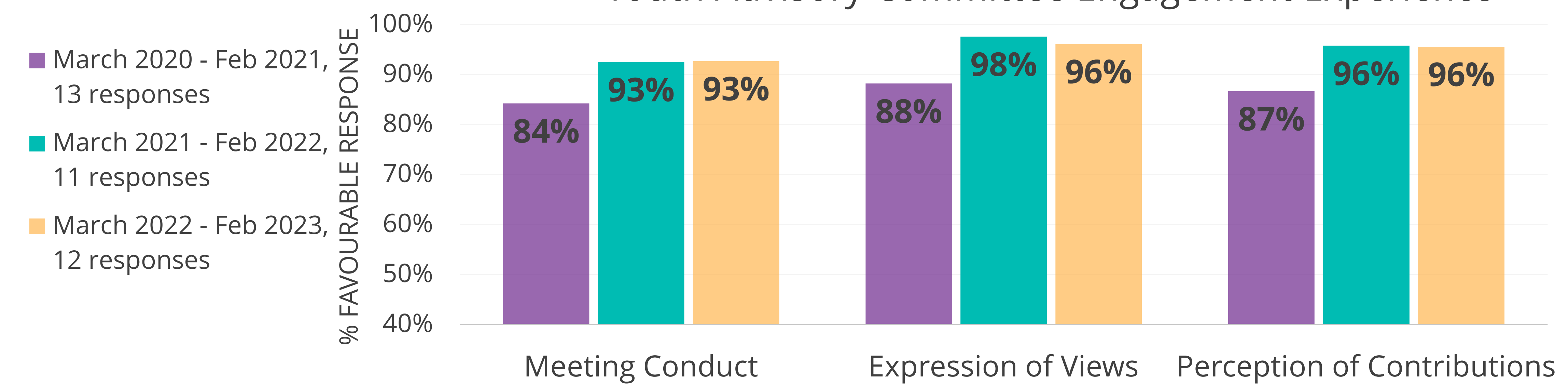
Public Patient Engagement Evaluation Tool

- **Self-report** questionnaire with items rated on a **5-point Likert scale** (1 = strongly disagree; 5 = strongly agree)
- Aims to measure advisors' **perception of study engagement** by asking about meeting conduct, the expression of views, and feelings of contribution
- **Reviewed and modified by advisors** prior to initial administration to ensure questions were comprehensive and relevant

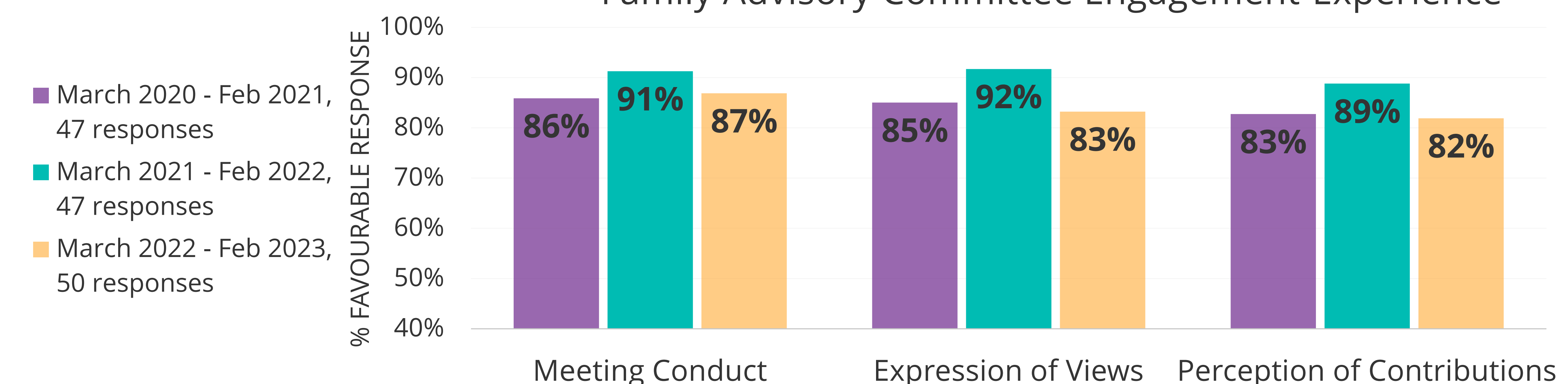
Youth advisors complete the PPEET every 3 months as per their recommendation.
Family advisors complete the PPEET every month as per their recommendation.

RESULTS

Youth Advisory Committee Engagement Experience



Family Advisory Committee Engagement Experience



DISCUSSION

NAVIGATE is a holistic approach to EPI care that supports recovery of the mind, body, and soul, a **major healthcare priority** emphasized by our YAC and FAC. Establishing advisory governances at the beginning of this project has provided incredible valuable in developing and carrying out all research objectives while empowering our youth and family advisors to be **leaders of change**.

CARE MANUAL AND DATA INTERPRETATION

- Provide direct feedback and support for NAVIGATE e-resources and digitization of client modules
- Guide recruitment strategies to meet target enrolment
- Regularly review and interpret results across study objectives

KNOWLEDGE TRANSLATION

- Support the translation of early results to clinicians, psychiatrists, and stakeholders
- Participate in our ECHO community of practice to support clinicians delivering EPI care

STORY-TELLING

- Create videos and media content to share their lived experiences with clinicians and clients in the NAVIGATE program

MEDIA AND ADVOCACY

- Participate in media interviews and podcasts to raise awareness for EPI services
- Wrote to Ontario's Ministry of Health to advocate for additional funding required to standardize EPI care

<https://www.epi-set.com/>

camh

CIHR IRSC
Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

EPI-SET

1. Abelson J, Li K, Wilson G, Shields K, Schneider C, Boesveld S. Supporting Quality Public and Patient Engagement in Health System Organizations: Development and Usability Testing of the Public and Patient Engagement Evaluation Tool. Health Expectations. 2016 Aug;19(4):817-827.. Strategy for Patient-Oriented Research: Patient Engagement Framework. (2014). CIHR. Retrieved from: http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf
2. . Strategy for Patient-Oriented Research: Patient Engagement Framework. (2014). CIHR. Retrieved from: http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf