

In-Person Workshop
February 21, 2024

EP-SET

Strategies for Engaging Youth 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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AGENDA

Project Overview

Establishing a Youth/Family Advisory Committee

Evaluating the Engagement Experience

Optimizing Engagement in Research

Discussion and Q&A

Learning Objectives

1. Learn strategies for initiating, establishing, and sustaining a youth/family advisory committee for a research study.
2. Evaluate and navigate the needs, priorities, and expectations of youth and family advisors across each stage of a research study.
3. Reflect on ways to ensure equal partnership between scientists and people with lived experience by valuing one another's expertise.

Getting to Know our Audience

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Project Overview

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Early Psychosis Intervention (EPI) Services

Life-Saving, but Recovery Limited

- **Outcomes for EPI users:**

- More likely to receive care from a psychiatrist
- Reduced burden on emergency departments
- Reduced all-cause mortality

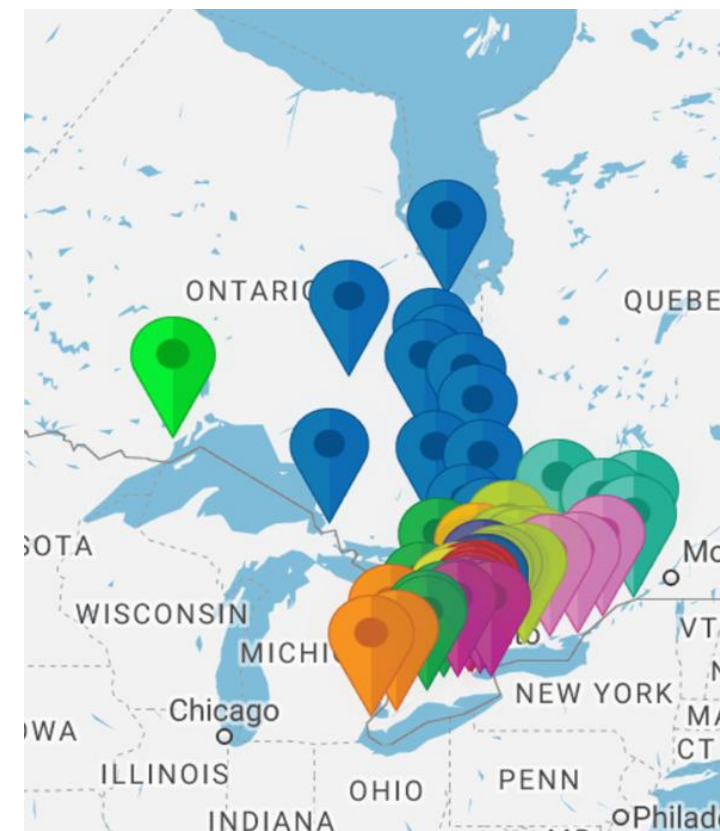
(Anderson, Norman, MacDougall, Edwards, Palaniyappan, Lau, & Kurdyak, 2018)

- While **EPI services have grown** in recent years, **recovery rates remain low**, and associated disability has not improved under routine clinical care

- The inconsistent delivery of high-quality, evidence-based care in EPI programs has resulted in a **low proportion of patients receiving recovery-based services**

- Only 18% are receiving comprehensive EPI services

(Craig, Garety, Power, Rahaman, Colbert, Fornells-Ambrojo, & Dunn, 2004)



Individualized Medication Treatment

- Reduce symptoms
- Prevent relapses

Individualized Resiliency Training

- Achieve personal goals by teaching clients about their disorder and its treatment
- Reduce self-stigmatizing beliefs
- Learn social and resiliency skills

Supported Employment and Education

- Develop education and employment goals
- Obtain jobs or enroll in educational programs

Family Education

- Teach families about psychosis and its treatment
- Encourage medication adherence & monitor signs of relapse
- Improve communication & problem solving

- NAVIGATE recipients remained in treatment longer, experienced greater improvement in quality of life and psychopathology, and experienced greater involvement in work and school compared with community care

Kane et al., *Am J Psychiatry*, 2015

EPI-SET Study Objectives

1

Implementation and Fidelity Outcomes

Assess whether implementation of NAVIGATE leads to improvement in fidelity to the EPI standard (using the First Episode Psychosis Services Fidelity Scale (Addington et al.)); also assess factors that may impact implementation

2

System Level Outcomes

Compare system use – i.e. days in hospital, emergency department visits, suicide attempts, system costs at Ontario EPI NAVIGATE sites (and non-NAVIGATE sites) using data held at ICES

3

Patient Level Outcomes

Determine longitudinal change in functioning and symptoms among NAVIGATE patients

4

Youth and Family Engagement

Evaluate patient and family member engagement according to the SPOR framework

Service users get involved in research because they see value in the work, and the research is better because it focuses on service user priorities.

2

Establishing a Youth/Family Advisory Committee

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Establishing Advisory Committees

- According to Canada's **Strategy for Patient-Oriented Research (SPOR)**, involving service users in healthcare research is predicated on 4 guiding principles: inclusiveness, co-building, mutual respect, and support.
- We meaningfully engage patients and family members with lived experiences of FEP as **equal research partners**.

Youth Advisory Committee

- Established January 2019
- Between 14 and 35 years of age with lived experiences of FEP
- Towards the end or have completed an Ontario-based EPI program



Family Advisory Committee

- Established December 2018
- Have a loved one between 14 and 35 years of age who have past or current symptoms of psychosis

Establishing Advisory Committees

RECRUITMENT

1

- ✓ Establish recruitment timeline
- ✓ Determine eligibility criteria
- ✓ Outreach strategies for recruiting diverse voices
 - Recruitment flyer
- ✓ Accessibility needs

SCREENING

2

- ✓ Assess readiness
- ✓ Manage commitment expectations
 - Study length
 - Meeting frequency
- ✓ Manage role expectations
 - Advocacy vs advising
 - QA vs research

Establishing Advisory Committees

ONBOARDING

3

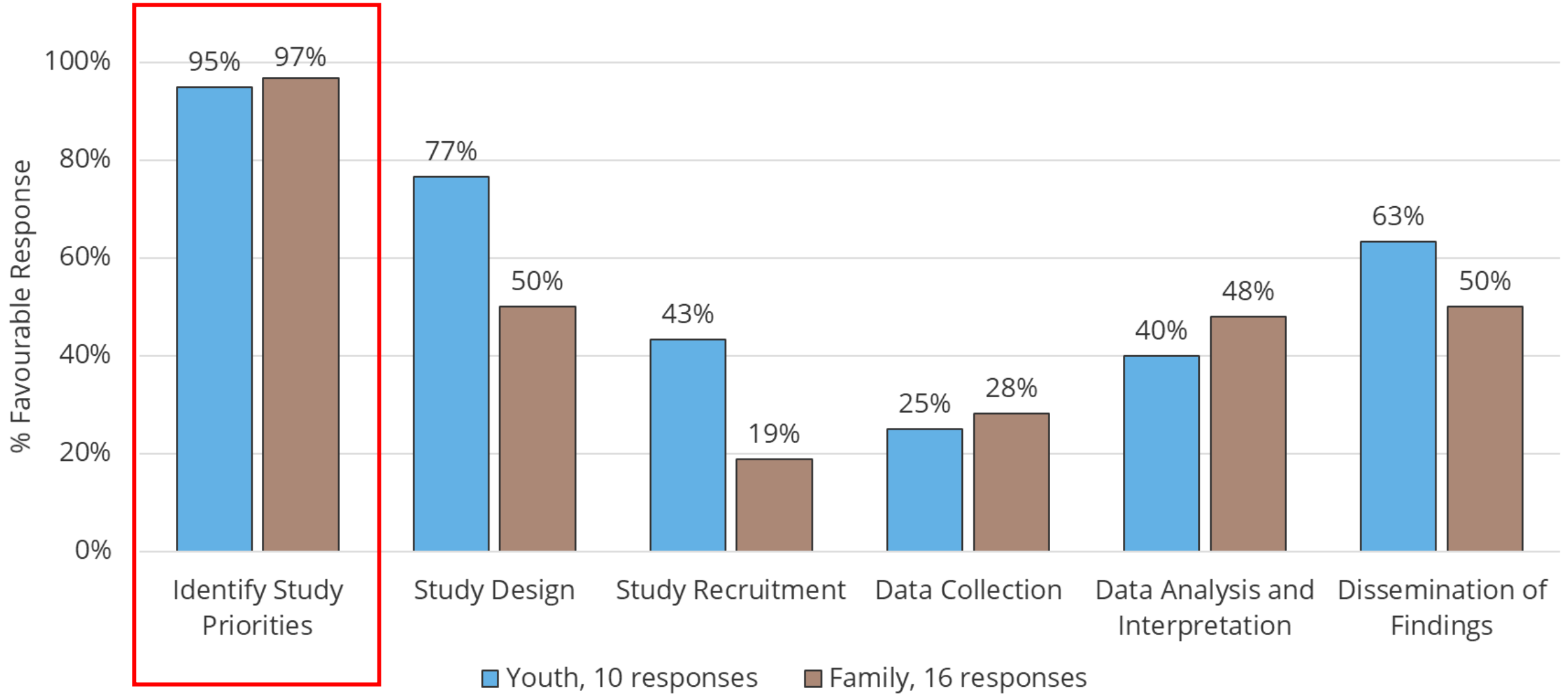
- ✓ Privacy and confidentiality agreement
- ✓ Terms of reference (ToR) and/or code of conduct
- ✓ Provide contacts for support
- ✓ Study resources
 - Project website
- ✓ Evaluation measures
- ✓ Discuss honoraria

RETENTION

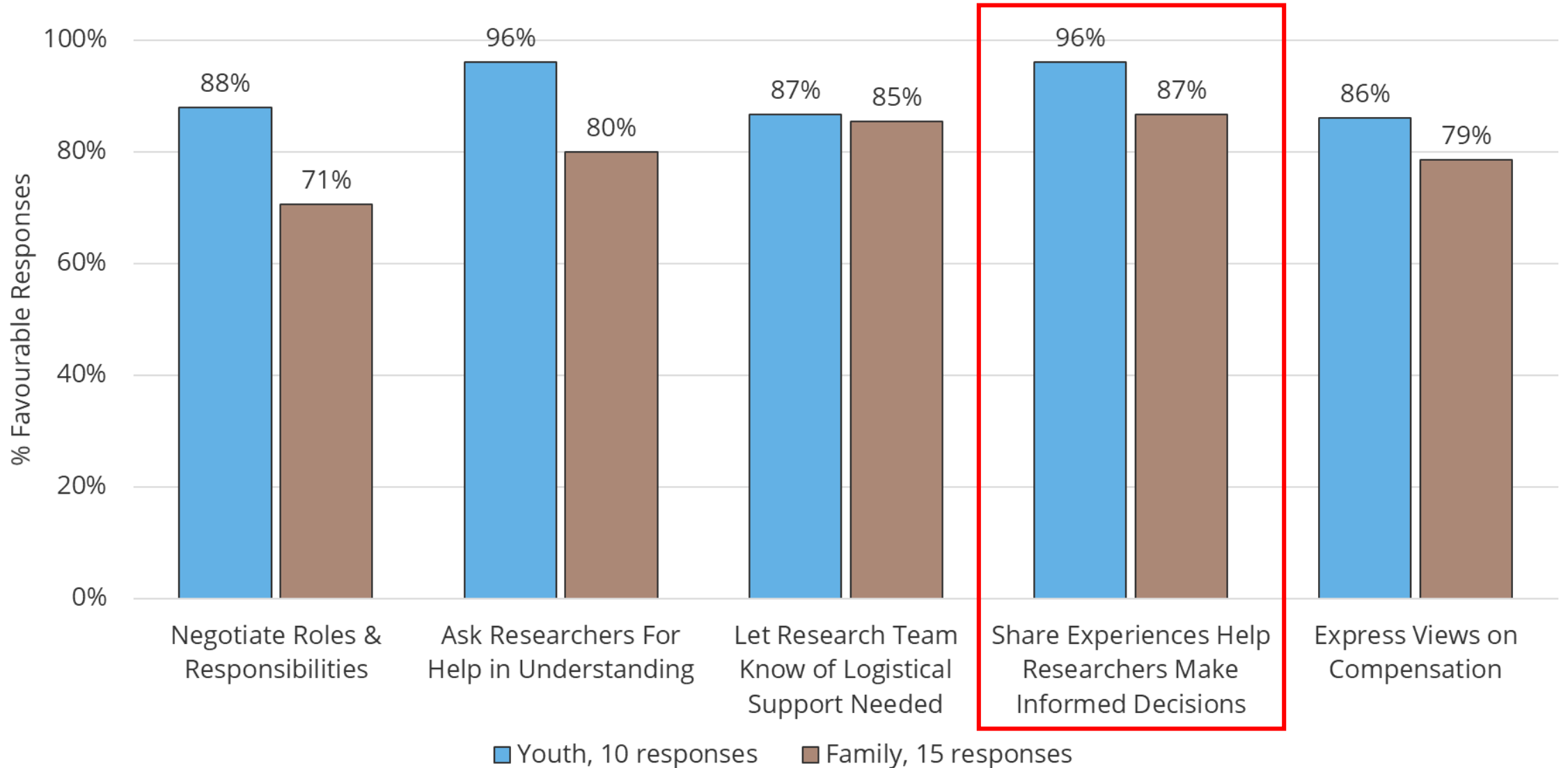
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- ✓ Communication channels
 - 1-on-1 check-ins
- ✓ Available institution-level support
- ✓ ToR/code of conduct collaboration
- ✓ Regular honoraria processing
- ✓ Align study activities with interests

Baseline Survey: Project Contributions



Baseline Survey: Support Needs



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Evaluating the Engagement Experience

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Evaluating Youth and Family Engagement

By measuring the engagement of advisors, we seek to:

1. **Promote** authentic engagement;
2. **Understand** the role of individuals with lived experiences on research studies;
3. **Contribute** to literature on strategizing meaningful patient engagement in research.

Engagement Surveys

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graph TD; A[Engagement Surveys] --> B[What is our experience like within this collaboration?]; A --> C[In what ways do we influence this research study?]
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What is our experience like within this collaboration?

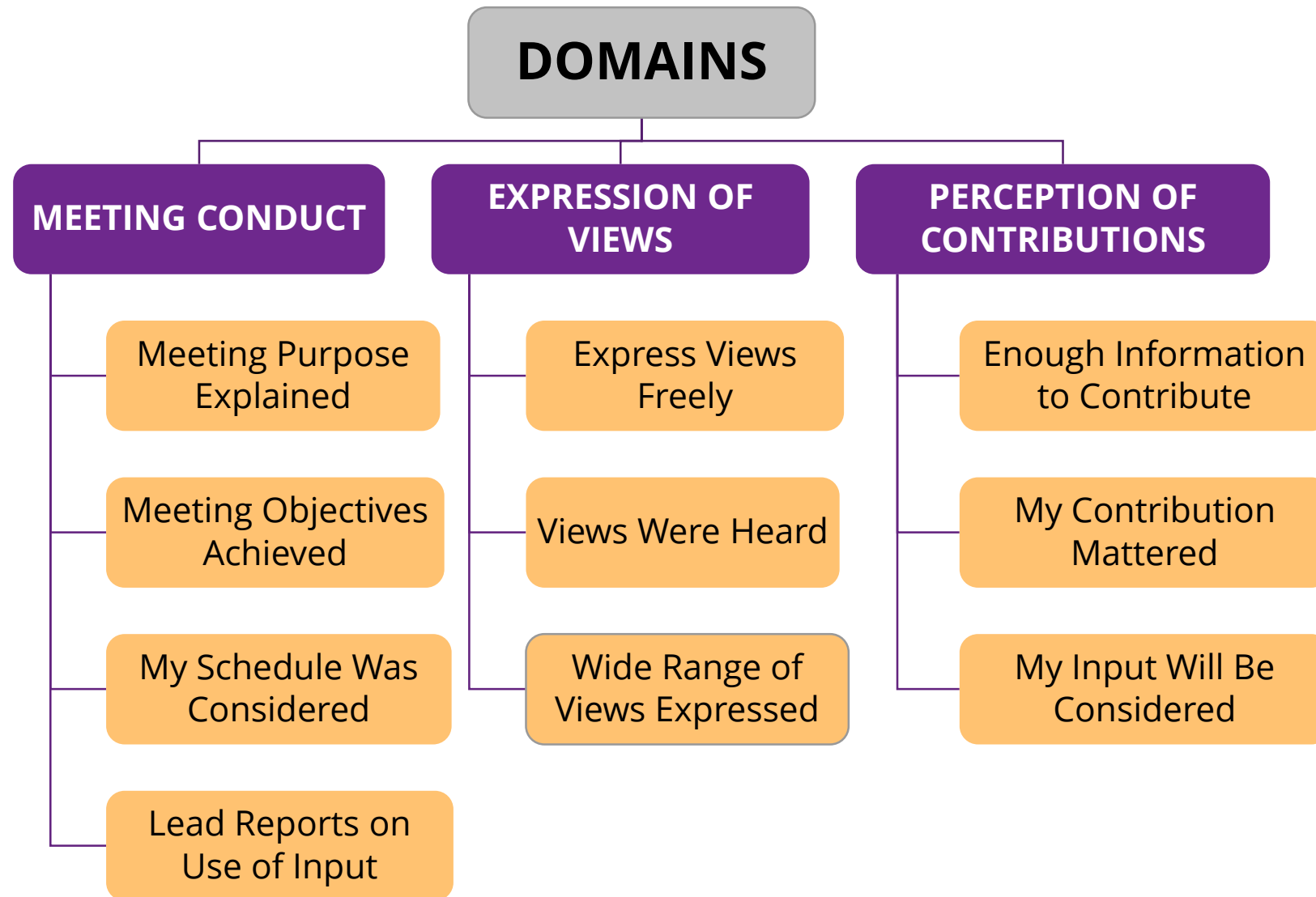
In what ways do we influence this research study?

Public Patient Engagement Evaluation Tool (PPEET)

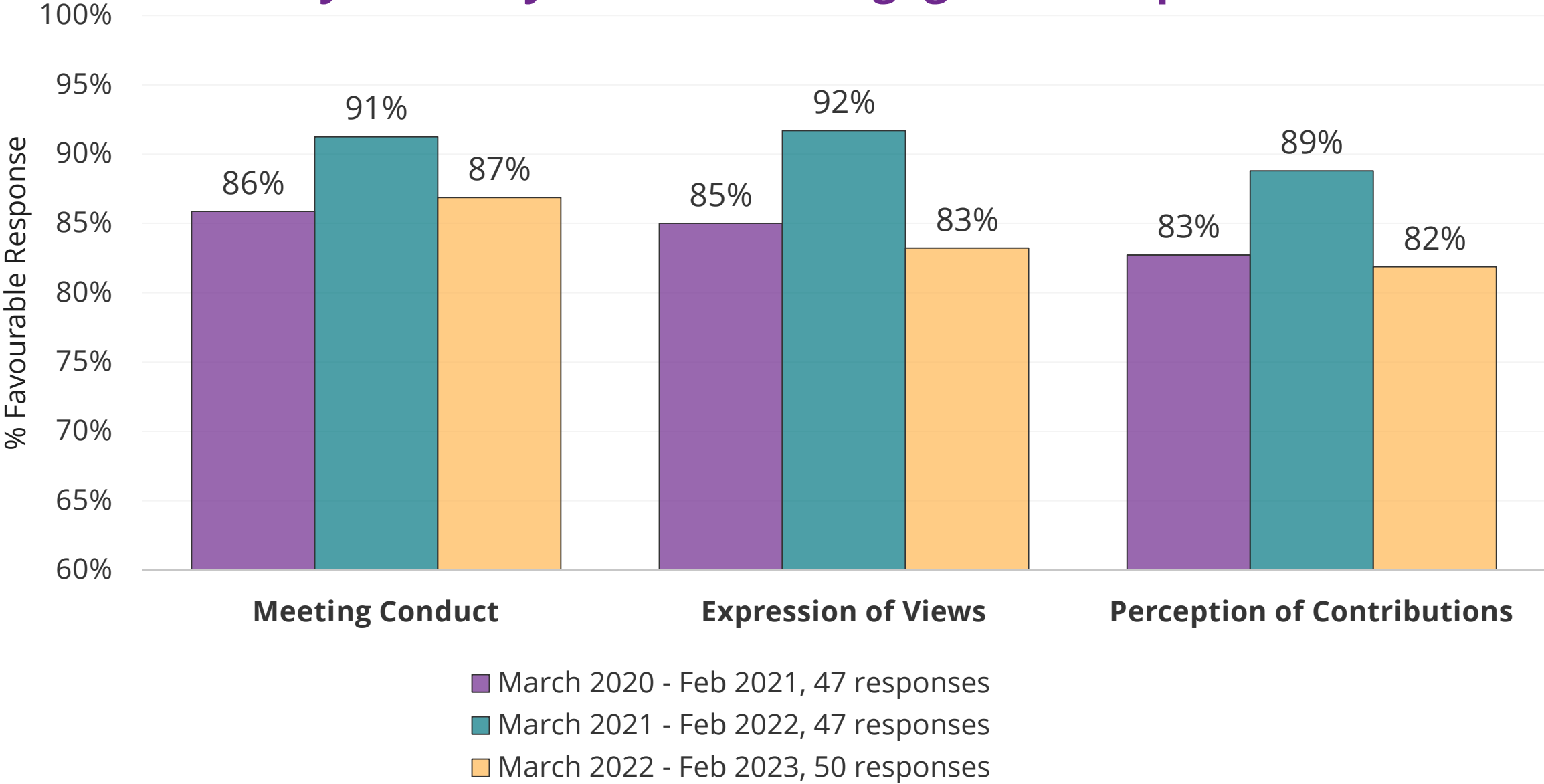
- **Self-report questionnaire** developed in 2011 at McMaster University and updated in 2018 based on results from an implementation study
- Recommended by collaborators from **Patient Expertise in Research Collaboration (PERC)**
 - Funded with support from **Ontario SPOR Support Unit (OSSU)**
- Questions reviewed and modified by advisors **prior** to initial administration in March 2020
- **Frequency** of survey completion was determined in collaboration with advisors
 - Youth Advisors: Every 3 months
 - Family Advisors: Every month
 - Advisory Leads: Every month

1 Strongly Disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly Agree
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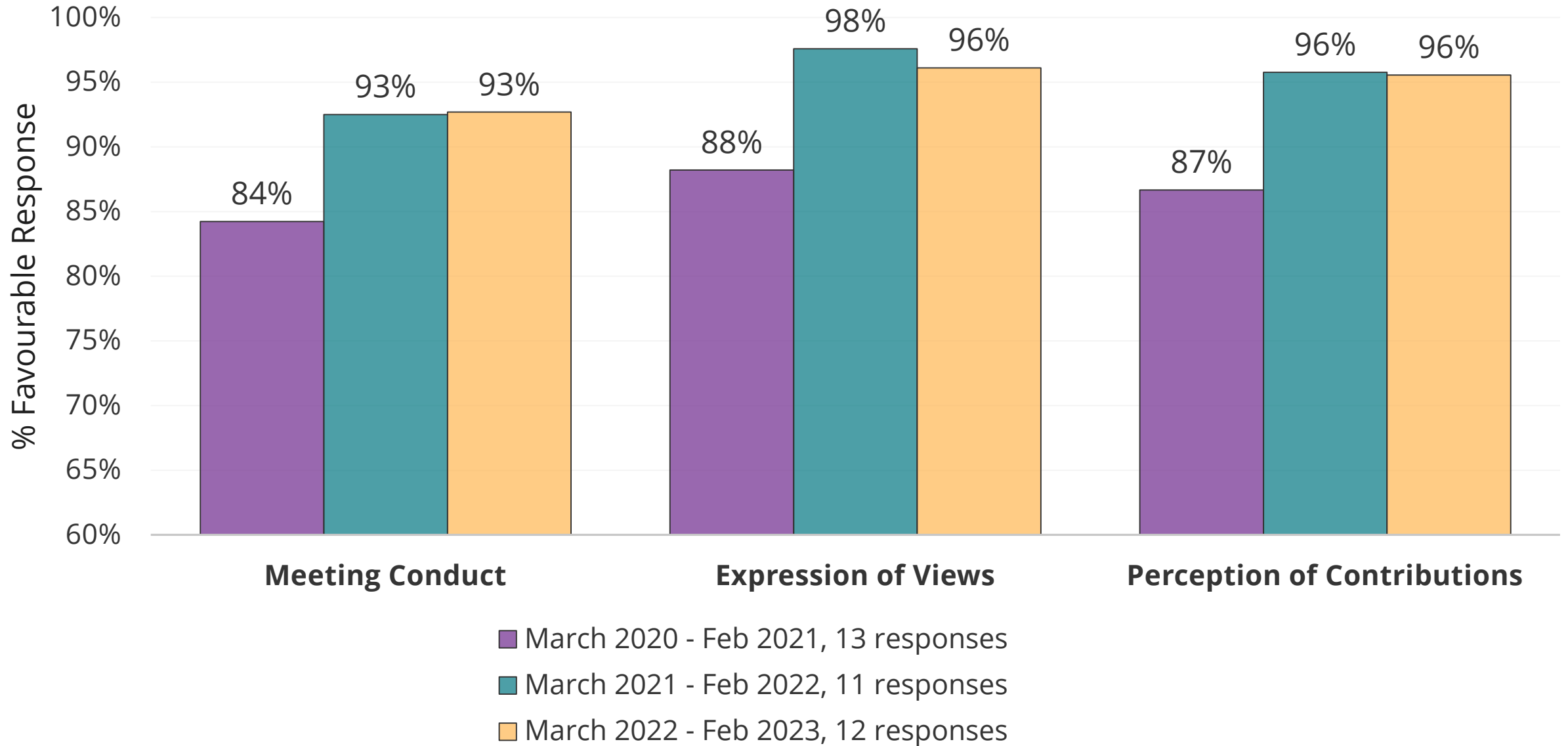
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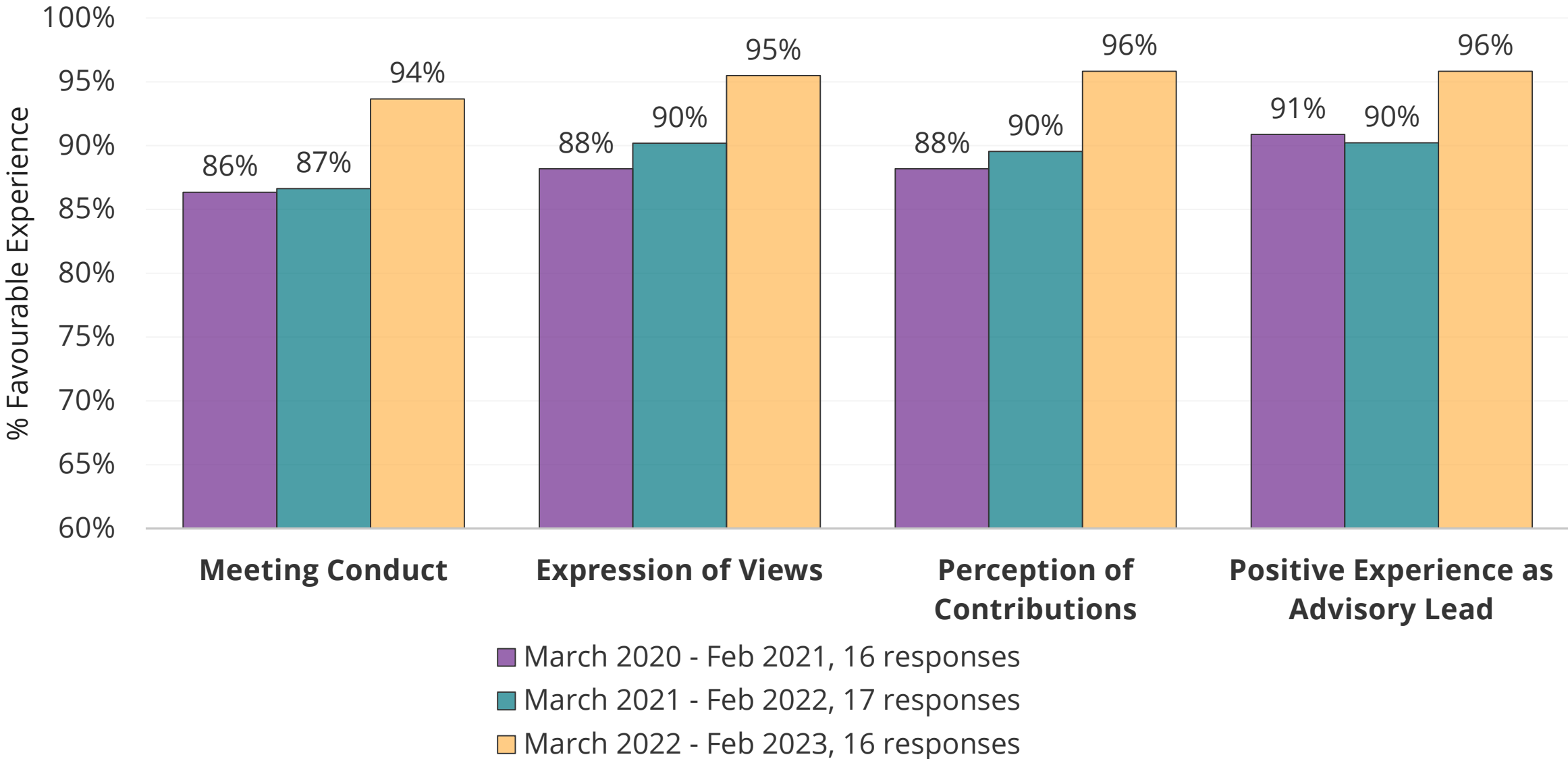
Family Advisory Committee Engagement Experience



Youth Advisory Committee Engagement Experience



Advisory Leads' Engagement Experience



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Optimizing Engagement in Research

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Our Engagement Experiences

Foster Meaningful Relationships

- Equal partnership from the beginning
- Mitigating power imbalances

Capacity Building Opportunities

- Joining sub-committees and related initiatives
- Speaking directly with service providers (e.g., ECHO)
- Conference presentations and manuscript writing

Consider Multiple Perspectives

- Collecting feedback and sharing how recommendations were addressed/implemented
- Bringing research to life (e.g., data interpretation, KT)

Accessible Communication

- Using transferrable language when collaborating
- Streamlined communication channels across the research team

Budgeting for Financial Resources

- Honoraria for advisors
- Dedicated research staff support (e.g., research analyst)

Your Engagement Experiences

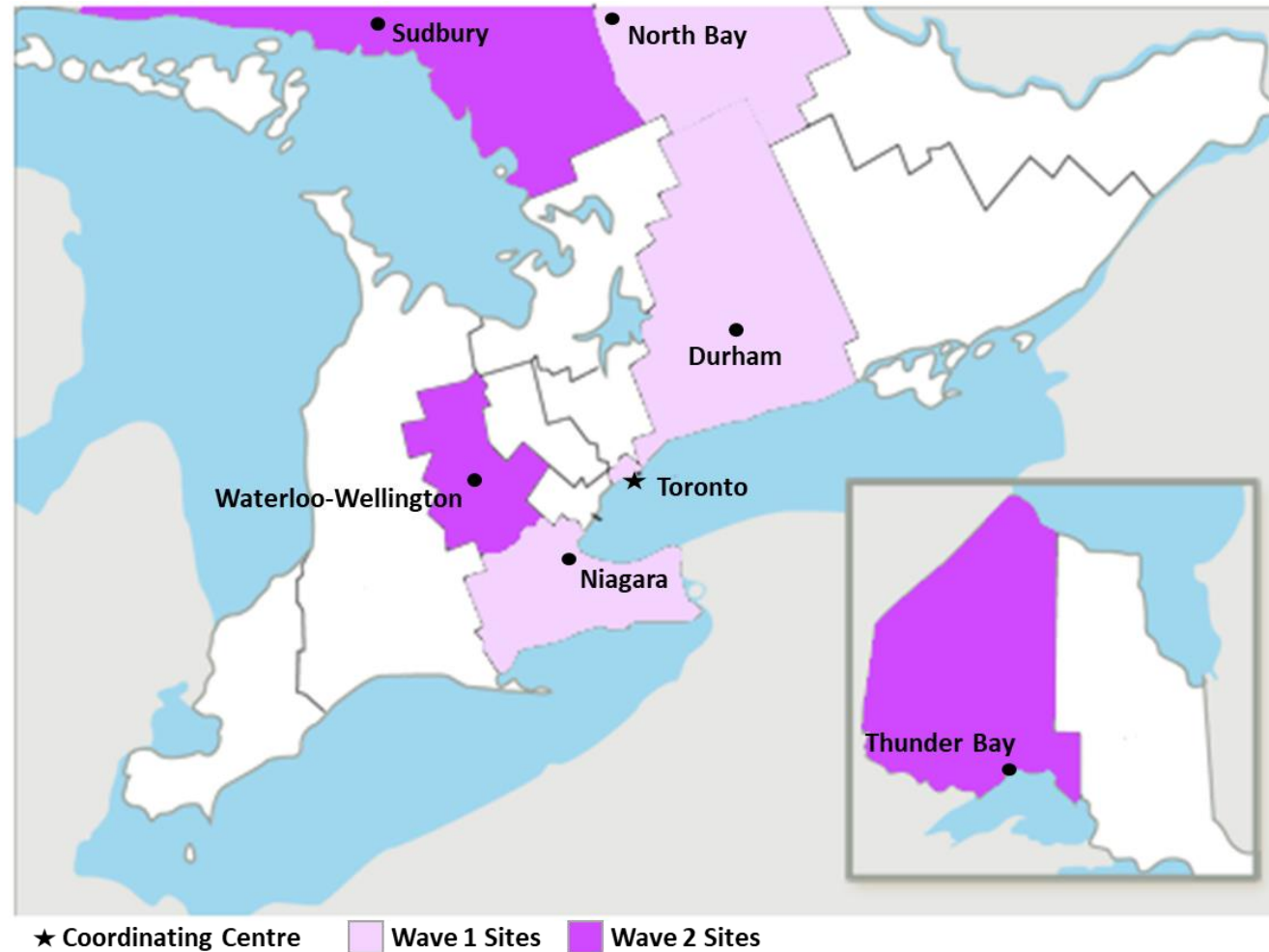
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Thank You to our Dedicated YAC and FAC Members!

Our advisors are located across Ontario.

Youth Advisors

- Victoria B
- Sara T
- Victoria V
- Tallan A
- Griffin M



Family Advisors

- Nicolle P
- Marie C
- Stacey O
- Andrea M
- Marylou C
- Claudia S
- Sonia C
- Trish N

Thank you!

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