

Co-designing recommendations with youth: how to *choose* and *use* patient-reported measures in youth mental health services

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INTRODUCTION

- In many youth services, patient-reported measures are used to improve the quality of care(1). These measures are an important way to include youth perspectives in decisions about care and show that a service values youth perspectives.
- However, these measures often are not completed by youth - rates of missing data are as high as 99% (2). Youth may not complete these measures for any number of reasons: they feel the measures do not respond to their needs or priorities; the format/design of the measure may not fit their preferences; they feel that the measures are not relevant to their clinical care and recovery (3), or any other reason.
- Often, these measures are integrated with limited input from youth.
- The goal of this project is to understand what youth want: what kinds of measures they want and how they want them to be used, to rectify the epistemic injustice that comes from only having clinician perspectives reflected in data shaping care and services.

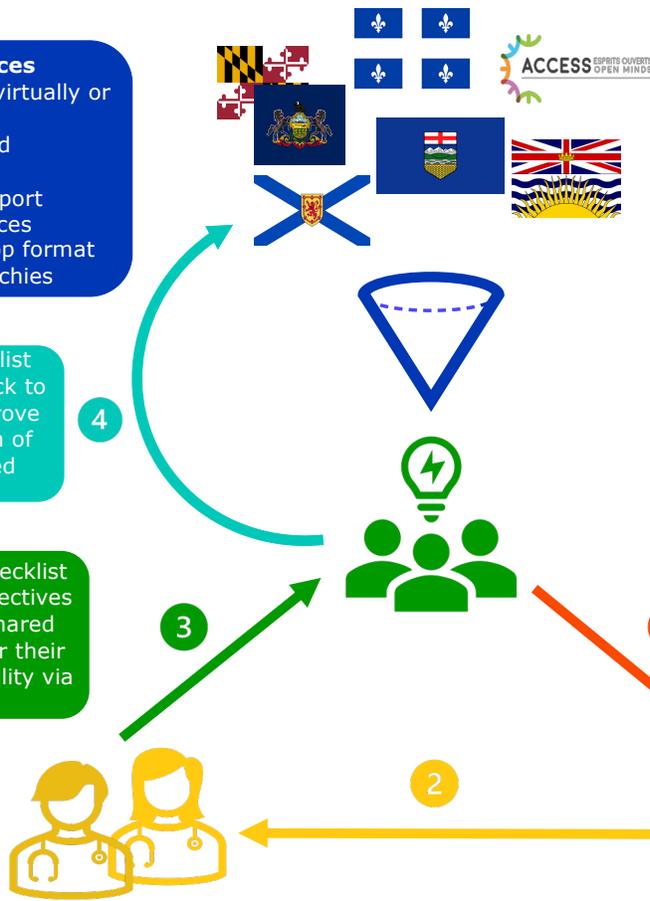
PROCESS

Equity Practices

- Workshops offered virtually or in person
- Asking about needed accommodations
- Providing travel support
- Centering youth voices
- Choosing a workshop format that removes hierarchies

4
The final checklist will be taken back to services to improve implementation of youth-reported measures.

3
A version of the checklist with clinician perspectives included will be shared back with youth for their ratings of acceptability via a survey.



1
Young people who have used Integrated Youth Services or Early Intervention Services for psychosis in a given network will be brought together in a Nominal Group Technique workshop to discuss what they want to see from youth reported measures in their youth service. We will run up to ten workshops; each workshop will only have young people from a specific location and service.

2
Youth recommendations will be shared with clinicians and service designers who will discuss the acceptability of the recommendations in individual interviews.

DISCUSSION

This project puts youth voices at the center of improving practices for implementing measurement-based care, with the goal of increasing epistemic justice.

In addition to the process being focused on epistemic justice, we have also built that value into:

- The team, which includes youth engagement specialists and people with lived experience
- Consulting with other people with lived experience both in individual meetings and group settings

Consultations have identified new avenues for making the workshops more interactive; strategies for improving the questions asked in the workshops; engaging methods for recruitment; and considerations on address the needs of young people who have low literacy or have difficulty organizing their thoughts.

We anticipate that the findings from this project will be useful for both current and future services which seek to implement youth-reported measures in ensuring that these measures, and how they are implemented, meet the needs of young people.

1. Parikh A, Fristad MA, Axelson D, et al.: Evidence Base for Measurement-Based Care in Child and Adolescent Psychiatry. Child Adolesc Psychiatr Clin N Am 29: 587-599, 2020.
 2. Kiseley S, Looi JC: Latest evidence casts further doubt on the effectiveness of headspace. Medical Journal of Australia 217: 388-390, 2022.
 3. Whitmyre ED, Esposito-Smythers C, López R, et al.: Implementation of Measurement-Based Care in Mental Health Service Settings for Youth: A Systematic Review. Clin Child Fam Psychol Rev 27: 909-942, 2024.6