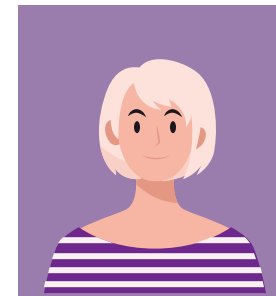
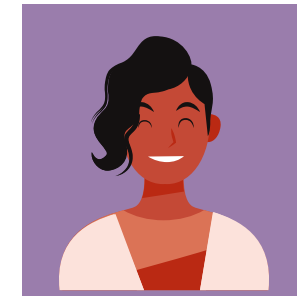


Fairness Dashboard: Focus Group Update & Advisor Feedback



camh
mental health is health

Icebreaker: As we gear up for Autumn, what are you looking most forward to?



About Today's Meeting

- Sharing initial findings from the first two focus group discussions we've hosted
- Sharing findings and feedback from the *Advisor Experience* survey

Recapping: Project Purpose

The screenshot displays the 'The Fairness Dashboard' interface. On the left is a purple sidebar with navigation buttons: a home icon, a question mark icon, and four text-based buttons: 'Why do we need this dashboard?', 'Where does the data come from?', 'Fair use data framework', 'Who created this dashboard?', and 'Share Your Feedback'. The main content area has a title 'The Fairness Dashboard Client Sociodemographic Data' next to a grid of diverse people icons. Below the title is a paragraph: 'This dashboard, developed collaboratively with lived experience advisors, is designed to reflect the multi-faceted realities of mental health care and encourage meaningful action toward health equity. The dashboard allows you to navigate client demographic data and explore critical questions which shape our understanding of health equity.' This is accompanied by an icon of a diverse group of people. Below this are three columns of text and icons: 1. 'While reviewing the data, consider the following:' with a purple house icon labeled 'Emergency and Acute Care Services'. 2. 'Who is accessing care and who is not?' with a green house icon labeled 'Depression Care Services'. 3. 'How do care outcomes differ and what factors influence the care services?' with a blue house icon labeled 'Schizophrenia Care Services'.

- Develop the Fairness Dashboard to visually present sociodemographic data in a clear, accessible format.
- Reduce biases that occur when data from smaller or marginalized groups are underrepresented in AI-based tools.
- Make the dashboard available to support scientists, clinicians, and administrators in research, developing Fair-AI tools, and improving care outcomes.

Recapping: Project Achievements to Date

ONGOING

Engage equity-deserving groups to provide lived-experience perspectives on the research process

SEPT 2023 – MAR 2024

Co-developed recommendations on engagement and design principles

ONGOING

Build partnerships within CAMH (e.g., Shkaabe Makwa) to support the integration of diverse perspectives

APR 2024

Welcomed new team member, Iman, to support development of the dashboard

MAR – JUN 2024

Created preliminary visualizations and our first **dashboard mock-up**

ONGOING

Recruit participants and **conduct focus groups** (2 complete to date)

Recapping: Work to be Completed

JUN – NOV 2024

Co-develop advisory video for dashboard users

SEPT – NOV 2024

Conduct 6-8 additional focus groups with targeted recruitment efforts

OCT – DEC 2024

Translate findings into new version of dashboard mock-up in Tableau

JAN – FEB 2025

Host participatory and user-testing workshops to co-develop a health equity framework and test usability

TBD

Launch pilot of Fairness Dashboard at a knowledge user forum to share findings and gather feedback

TBD

Future project planning

Fairness Dashboard

Focus Group Discussions

Focus Group Purpose

- Host up to 10 focus groups each with 4-5 diverse participants (18+, with lived experience of a mental health condition)
- The purpose of the focus groups are to learn about participants perspectives and opinions on the collection, use and visualization of health equity data to improve clinical care, decision-making, and outcomes through predictive models

Focus Group Questions

Theme 1: Understanding of Health Equity Data

- 1) When you hear the term equity, what do you think of?
- 2) What do you think of the Health Equity form?
- 3) How do you think this data is currently used at CAMH?
- 4) What do you think are the benefits or drawbacks of collecting this data?

Theme 2: Perceptions of Visualizing Health Equity Data

- 4) What are your initial reactions or thoughts about the visualization of this data?
- 5) What do you think this visualization is trying to communicate?
- 6) What do you think are the best or worst outcomes of clinicians or researchers using this data?

Theme 3: Potential Uses of the Fairness Dashboard

- 7) What is your biggest fear when it comes to [Michaels]'s use of the data dashboard?
- 8) What is your biggest hope when it comes to [Michaels]'s use of the data dashboard?
- 9) What steps do you think [Michael] should take to ensure they do not misuse the data or misinterpret the findings?

Theme 4: Final Thoughts and Perspectives

- 10) Are there any other aspects of your identity or personal experiences that have shaped your perspectives not mentioned during this discussion?
- 11) What do you hope our research accomplishes regarding the use of health equity data in healthcare?

Focus Group Initial Findings: Demographics

2 Focus Groups → 9 Participants

Race/Ethnicity (select all that apply)	Frequency
First Nation, Metis or Inuit	1 (11%)
Black-African	1 (11%)
Black Caribbean	3 (33%)
Middle Eastern	1 (11%)
South Asian	1 (11%)
Southeast Asian	1 (11%)
Latin American	1 (11%)
White European	1 (11%)
White North American	1 (11%)

Gender Identity	Frequency
Man	3 (33%)
Woman	5 (56%)
PNA	1 (11%)

Sexual Orientation (select all that apply)	Frequency
Gay	1 (11%)
Pansexual	1 (11%)
Queer	1 (11%)
Straight/Heterosexual	3 (33%)
PNA	4 (44%)

Family Income	Frequency
\$0-\$19,999	1 (11%)
\$20,000-\$39,999	1 (11%)
\$40,000-\$59,999	3 (33%)
\$150,000 or more	1 (11%)
PNA	3 (33%)

Housing Type	Frequency
Owns	5 (55%)
Rents	1 (11%)
Social Housing	1 (11%)
PNA	1 (11%)
Other	1 (11%)

Focus Group Initial Findings: Theme 1 - Participants' Understanding of Health Equity

camh Health Equity

Ontario Health (OH) requires all Toronto area hospitals to conduct this survey to help improve equitable access to care. The information is reported in aggregate for to OH. No personal identifiers or other information that would identify a patient would be provided.

Completing this survey is completely voluntary. All questions are optional and your answers will not affect your care. If you decide to not answer a question, please select "prefer not to answer".

Your answers will be documented in your CAMH health record and will be available to your care team.

Were you born in Canada?
 Yes No Prefer not to answer Do not know
 If no, then what year did you arrive in Canada?
 Where were you born?

What is your citizenship status?
 Canadian Immigrant Refugee Unknown Prefer not to answer Do not know

Do you identify as First Nations, Métis and/or Inuk/Inuit?
 No Yes, First Nations Yes, Métis Yes, Inuk/Inuit Prefer not to answer Do not know

What is your ethnic or cultural background? (for example: Canadian, Chinese, East Indian, English, Filipino, French, German, Irish, Italian, Jamaican, Jewish, Polish, Portuguese, Scottish, etc.)

Which of the following best describes your racial group? (Check all that apply, for example if you are multi-racial or mixed race)
 Identifies only as First Nations, Métis and/or Inuk/Inuit
 Black-African (e.g., Ghanaian, Kenyan, Somali)
 Black-Caribbean (e.g., Barbadian, Jamaican)
 Black-North American (e.g., Canadian, American)
 Middle Eastern, Arab or West Asian (e.g., Afghan, Egyptian, Iranian, Lebanese, Persian, Turkish, Kurdish, etc.)
 Indian-Caribbean (e.g., Guyanese with origins in India)
 East Asian (e.g., Chinese, Korean, Japanese, Taiwanese, etc.)
 South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan, etc.)
 Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc.)
 Latin American (Hispanic or Latin American descent)
 White-European (e.g., English, Italian, Portuguese, Russian)
 White-North American (e.g., Canadian, American)
 Do not know
 Prefer not to answer
 Other:

Are there cultural/ethnic needs that we should be aware of to support your recovery/treatment?

Do you identify as a person with a disability?
 Yes No Do not know Prefer not to answer
 If you wish, please specify your disability:

camh Health Equity

Could you benefit from support related to any of the following? (check all that apply)
 None Developmental Disability Sensory Disability (low vision, blindness, deafness, hard of hearing, etc.)
 Alzheimer's Disease/Dementia Drug or Alcohol Dependence Do not know
 Autism Spectrum Disorder Learning Disability Prefer not to answer
 Chronic Illness (sickle cell, diabetes, ect.) Mental Illness Other:
 Cognitive Disability Physical Disability

Do you use the following assistive aids and devices?
 Visual Aid Pacemaker Sleep Aid/Device Other:
 Auditory Aid Communication Aid/Device Artificial limb/Prosthetic
 Dental Aid Comfort Aid Toileting Aid

Specify the aid:

What was your sex assigned at birth?
 Male Female Intersex Do not know Prefer not to answer

What is your gender identity? (check all that apply)
 Genderfluid or genderqueer Two-Spirit Other:
 Prefer not to answer Woman
 Man Questioning or unsure
 Nonbinary Do not know

Do you identify as transgender? Transgender is an umbrella term used to describe people whose gender identity or gender expression differs from the sex they were assigned at birth.
 Yes No Prefer not to answer

Which category(ies) best describe your sexual orientation? (check all that apply)
 Asexual Lesbian Same-gender loving Prefer not to answer
 Bisexual Pansexual Straight/heterosexual Other:
 Demisexual Queer Two-Spirit
 Gay Questioning or unsure Do not know

Do you currently have difficulty paying for basic needs?
 Yes No applicable, I do not have to pay for basic needs Prefer not to answer
 No Do not know

What was your family income before taxes last year?
 \$0 - \$19,999 \$60,000 - \$79,999 \$150,000 or more
 \$20,000 - \$39,999 \$80,000 - \$119,999 Do not know
 \$40,000 - \$59,999 \$120,000 - \$149,999 Prefer not to answer

How many people does your income support?
 1 2 3 4 5 6 7 8 9 10 +
 Prefer not to answer Do not know

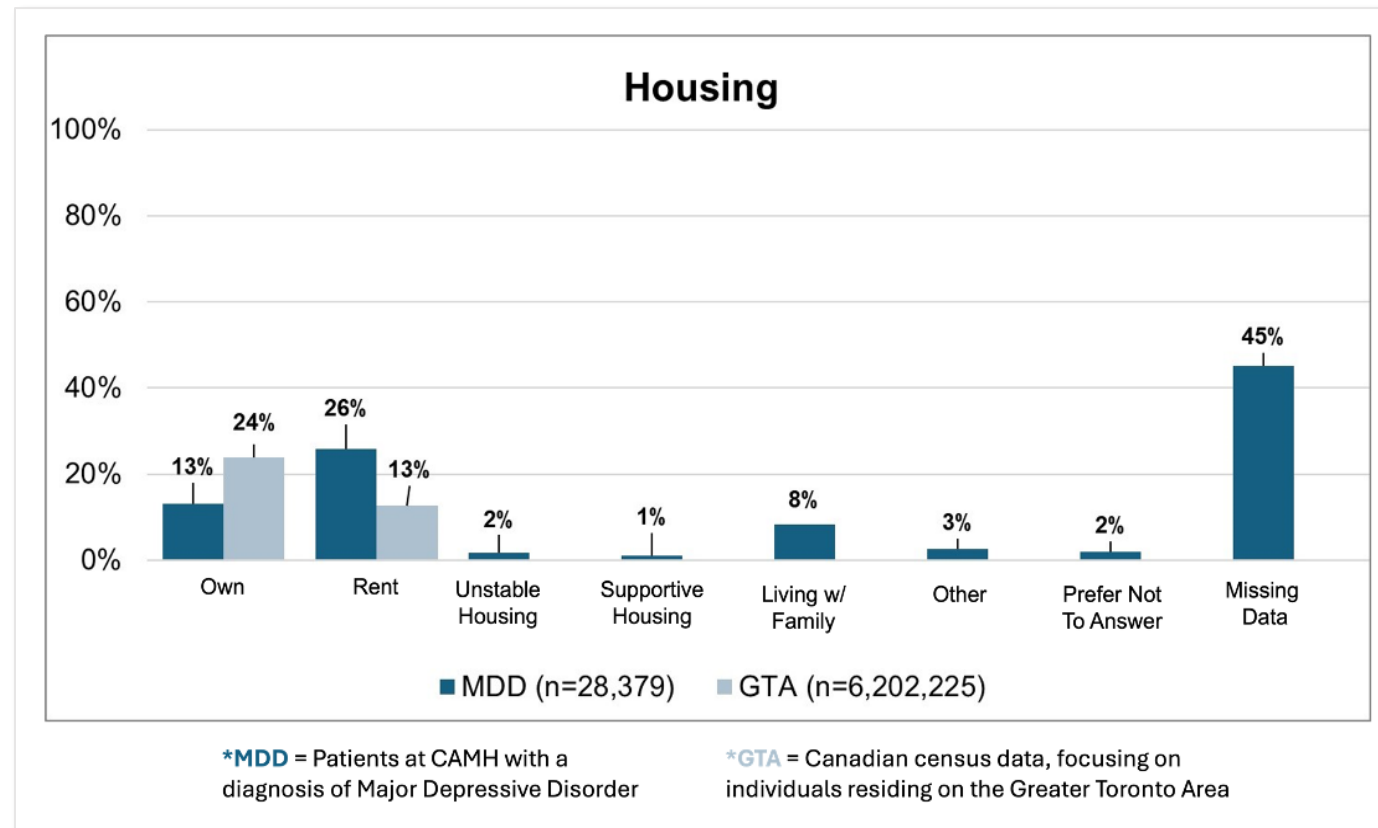
Income type:
 No income Disability insurance Prefer not to answer
 Employed Social assistance Do not know
 Insurance Pension (CPP, OAS) Other:

- Most participants emphasized the importance of equitable access to healthcare, regardless of demographic background.
- Some participants expressed concerns about potential unconscious biases in care, as well as issues surrounding the privacy and security of personal information
- Participants noted that AI lacks a human element, but with input from underrepresented groups and lived experiences, it can benefit healthcare systems.

"[...] I would say that equity in healthcare would be the ideal, where everyone has the same healthcare or same treatment regardless of their status or income or any other status that they hold."

"I think health equity could benefit from AI if enough voices are able to give information that is relevant to them."

Focus Group Initial Findings: Theme 2 - Perceptions of Visualizing Health Equity Data



- Most participants were unsurprised by the results presented in the visualization.
- Some participants described the visualization as “gloomy” and “depressing”
- Many recognized the impact that mental health status may have on access to housing.
- Few participants thought the ‘missing data’ was concerning, whereas others thought ‘missing data’ meant ‘missing housing’.
- Participants recognized the importance this data might have on personalizing care and services provided to patients.

“I think that the data identifies areas where clinicians can come in and provide services or focus in on some services, and to be able to have an impact on outcomes.”

“We do have to just be mindful of who we're missing in this data too, and that should be a consideration that clinicians and researchers consider.”

Focus Group Initial Findings: Theme 3 - Potential Uses of the Fairness Dashboard

User Persona: Michael



Michael Budny MD, MBA
Executive Leader at CAMH

About Michael

- Michael has worked at CAMH for 10 years
- He previously worked as a psychiatrist and transitioned to a leadership role after completing his Master's in Business Administration (MBA)

Michael's Views on Health Equity

- Michael has a basic understanding of health equity. He knows it's important but doesn't know much.
- Michael must ensure that his work aligns with CAMH's strategy. One of CAMH's strategic goals is to provide more equitable care.

Michael's Challenges with the Dashboard

- Michael might not spend enough time learning about the dashboard and the data.
- Michael doesn't have much experience communicating data findings to his colleagues

Michael's Use of the Dashboard

Michael wants to use the dashboard data to find out which population groups might benefit most from a culturally specific clinic at CAMH.

Michael will look at ethnicity data of people with schizophrenia spectrum disorders who receive care in the Psychosis Care clinic to see which ethnic group might benefit most from culturally specific care.

5

- Some participants felt that if Michael is unable to communicate data findings, or spend enough time reviewing the data, he shouldn't have access to the data.
- Participants were concerned about the potential for misunderstanding/bias when Michael is interpreting the data.
- Participants felt, that at the very least, Michael should engage with clinicians and people with lived experience before acting on the data findings.
- They also felt that Michael should take a data analytic training or be provided with resources to support his analysis.

"I think reading it, I initially was kind of concerned cause he doesn't have much background in health equity, so just basic things that ran into my mind was like, you know, training, even at the baseline to broaden his own understanding of the importance of health equity."

Focus Group Initial Findings: Theme 4 - Final Thoughts and Perspectives



- Participants discussed how personal experiences, particularly with underrepresentation and mistrust in healthcare, shape their views on the use of health equity data.
- Some participants highlighted the positive impact of having healthcare providers from similar cultural backgrounds.
- Participants expressed hope that this research will lead to meaningful, actionable changes to improve care for underserved groups and ensure their voices are heard.
- Some expressed skepticism about AI and data collection, regarding the lack of representation in those designing the systems and whether the data leads to actionable change.

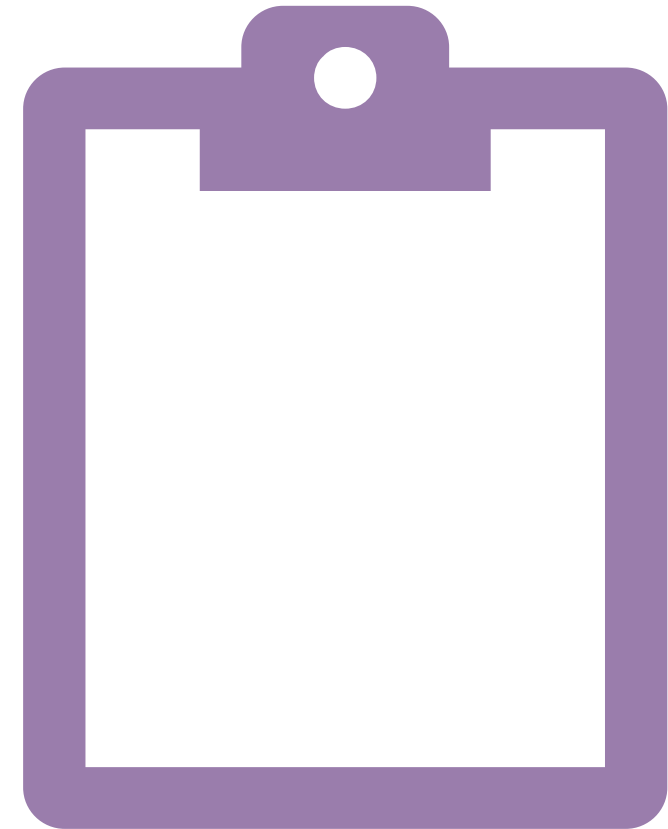
"I think [this research] will really help show, kind of where specific inequities are in the field of healthcare [...] and how to maybe eliminate those barriers by more like culturally aware doctors or clinicians that are involved in healthcare."

"I'm skeptical about AI because the people who are building it aren't representative of the overall community."

Advisor Experience Survey Results

Advisor Experience Survey: Purpose

To evaluate your experience as an advisor supporting the *Fairness Dashboard* project and to gather feedback on ways we can improve your experience.



Survey Results: Meeting Facilitation

I had enough information to contribute to the topics discussed during the advisory meetings.



The study and meeting information provided to me has been appropriate and understandable.



The advisory meeting facilitation is compassionate and inclusive.



The purpose of the advisory meetings is clear.



Strongly Agree **Agree** **Neutral** **Disagree** **Strongly Disagree**

Survey Results: Meeting Collaboration

A sense of partnership is felt among the research team and the advisors.



I feel comfortable speaking up and contributing during meetings.



All advisors are given equal opportunities to provide their input.



The research team has created a respectful and welcoming environment.



The research team listens to and absorbs my input during the meetings.



The research team encourages the expression of differing viewpoints.



Strongly Agree **Agree** **Neutral** **Disagree** **Strongly Disagree**

Survey Results: Meeting Logistics

The size of the advisory committee (i.e., # of advisors) is adequate.



The length/frequency of the meetings allow me to meaningfully contribute to the study.



The team works with me to accommodate any challenges and ensure it is easy for me to participate.



Advisory meetings are scheduled to enable maximum participation.



Strongly Agree **Agree** **Neutral** **Disagree** **Strongly Disagree**

Survey Results: Meeting Outputs

The amount of time provided to review communications and materials outside of the advisory meetings is sufficient.



The follow-up and communications after each advisor meeting are sufficient.



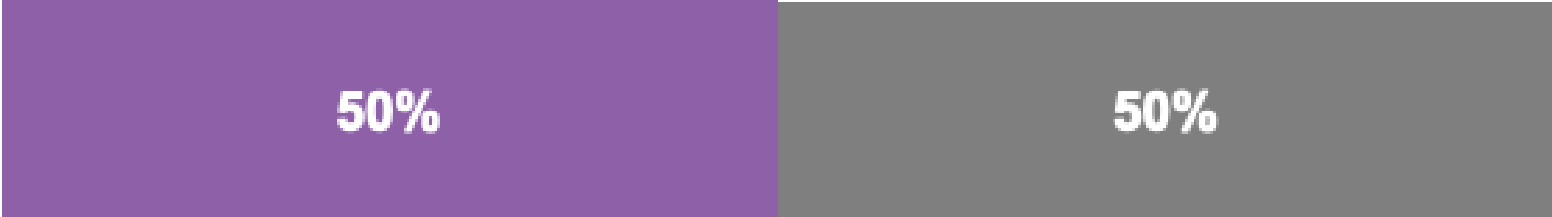
The outcomes or outputs of the advisory meetings accurately reflect our discussions.



Strongly Agree **Agree** **Neutral** **Disagree** **Strongly Disagree**

Survey Results: Satisfaction

Are you satisfied with your experience as an advisor on the research project?



Yes



Felt *heard* and *listened* to

Productive use of time

Contributing to something unique

Neutral



Unsure of the bigger picture

Need more clarity

Advisor Experience Survey: Feedback

Do you believe lived-experience advisors can improve the quality and outcomes of research?

General consensus was **YES!**

Improve the quality of research

Improve the outcomes of research

Provide nuanced and unique perspectives

Ensure research is grounded in real world experiences

Ensure research is practical, relative and applicable

What can the research team do to improve your overall experience as an advisor on the project?

Provide up-to-date education resources, including inclusive and person-centered language guides.

Conduct 1-on-1 check-ins with advisors pre-or-post advisory meetings to level set.

Continue communicating project updates to the advisors regularly