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Reflecting on the Process

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Appendix 1:

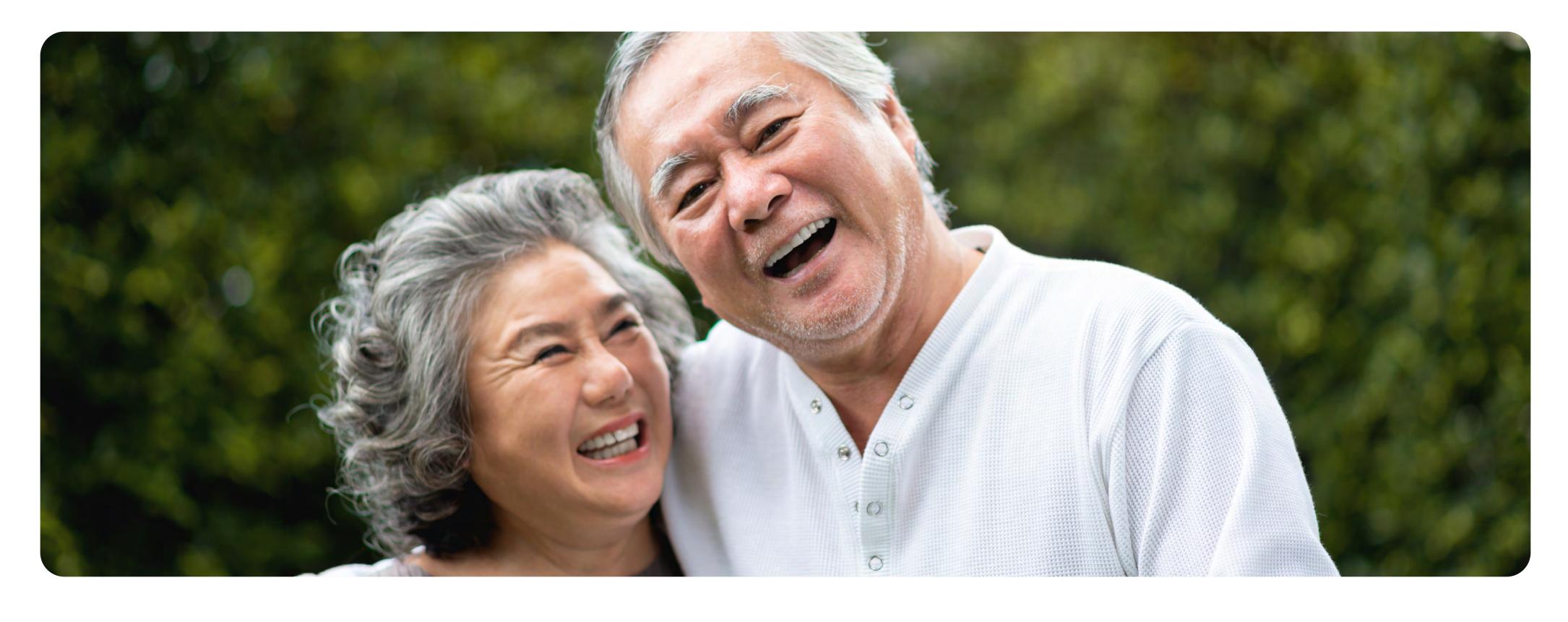
Detailed Quantitative Methods

Appendix 2:

Detailed Co-Analysis Methods

Appendix 3:

PAC Recommendations for Communicating ON-MARG



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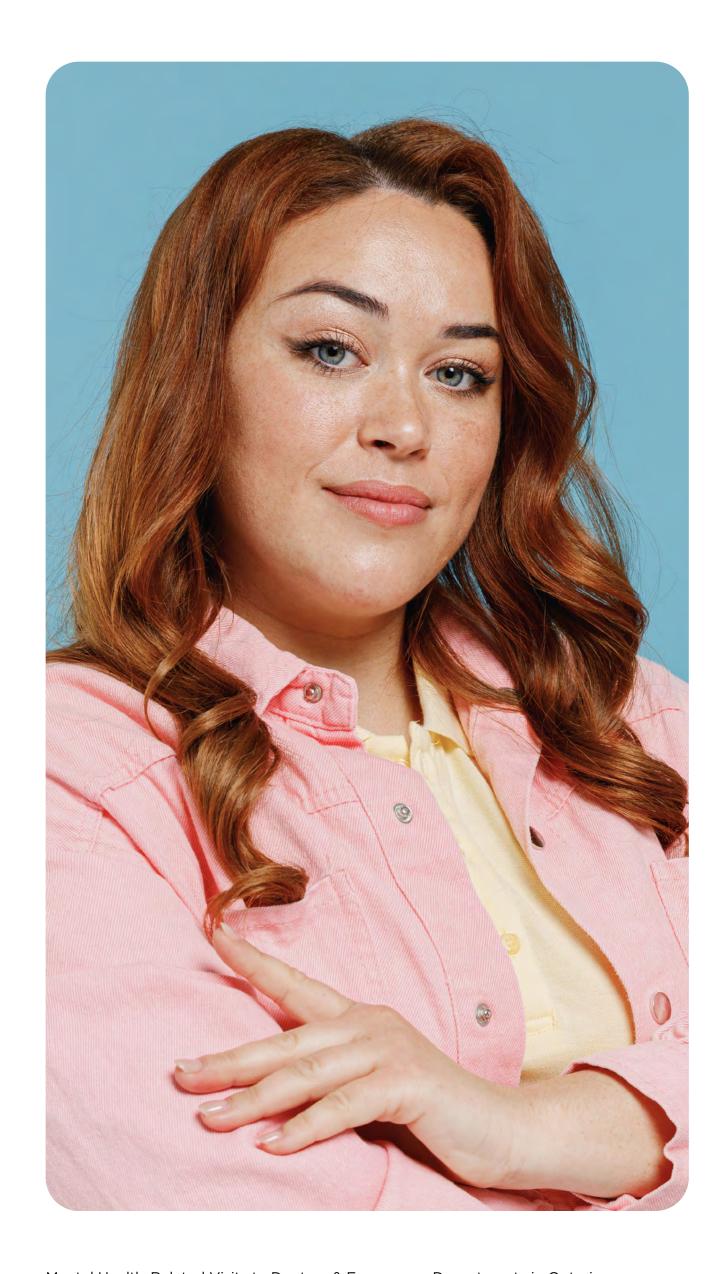
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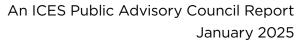


Who We Are

Committed to working with scientists, partners, and communities to help explore today's problems and inform solutions for better health and healthcare tomorrow.

ICES is an independent not-for-profit research and analytics institute and registered charity with seven sites across Ontario. Formed in 1992, ICES is governed by a Board of Directors and guided by a Scientific Advisory Committee and a Public Advisory Council, representing diverse regions and communities across Ontario. ICES is powered by a community of research, data, and clinical experts. Many are practicing clinicians who understand the everyday challenges of healthcare delivery. Together, we produce insightful research and analytics that informs thoughtful policy.







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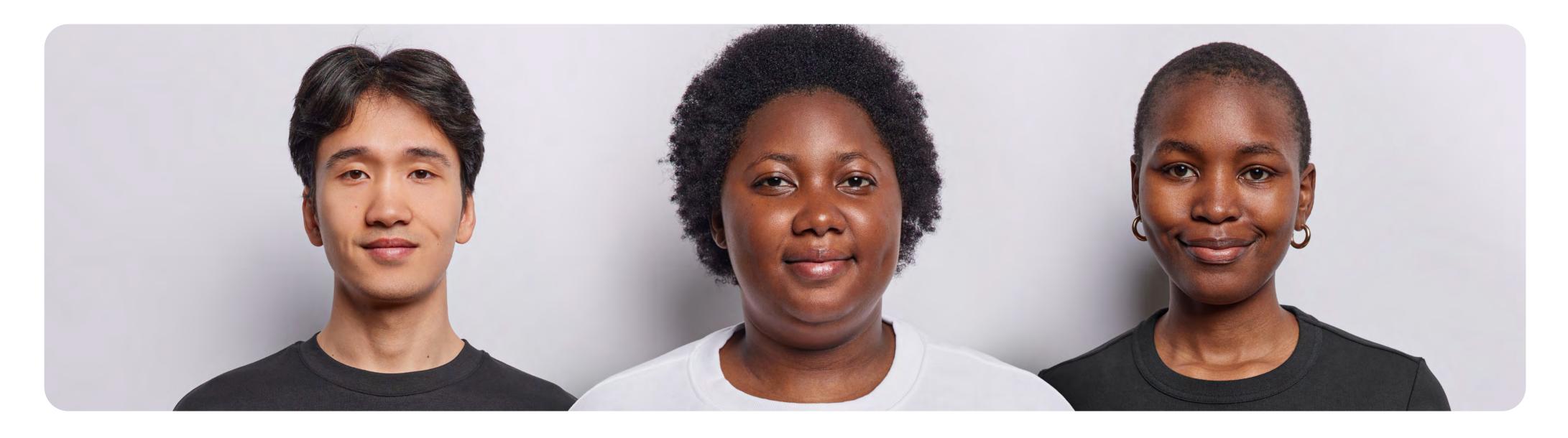
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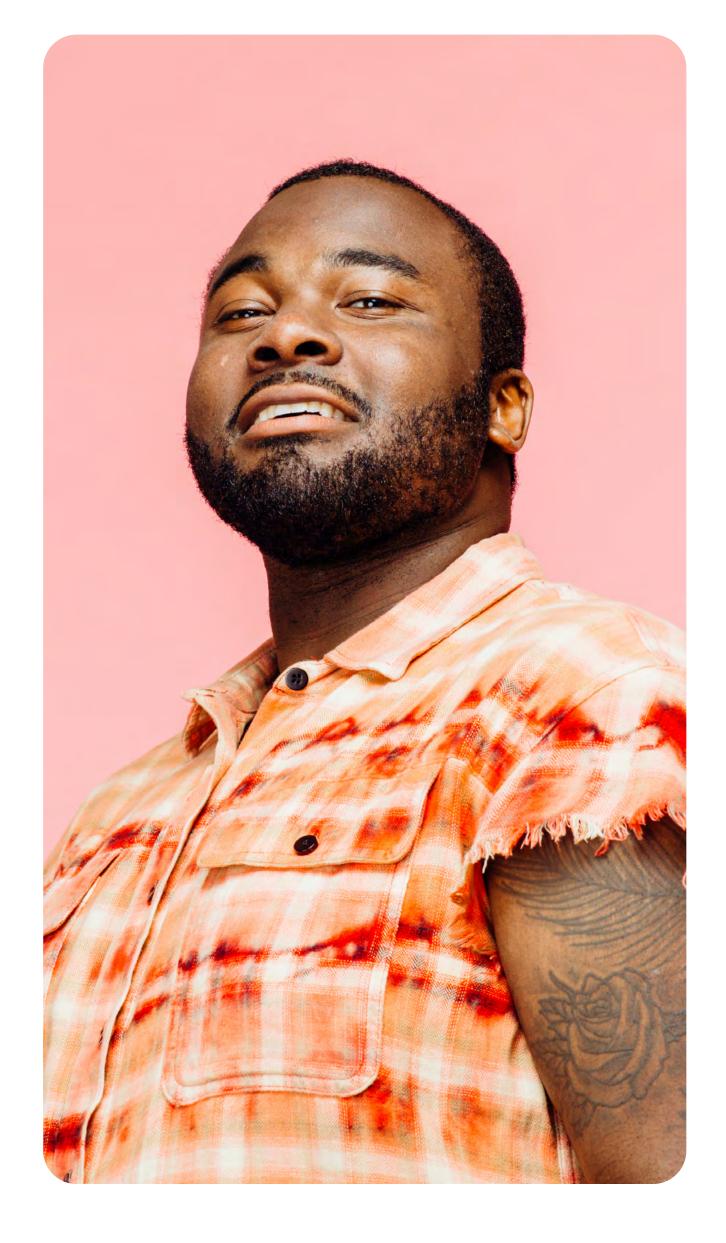
ICES Public Advisory Council

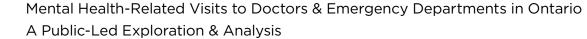
This report is the result of extensive collaboration with the dedicated individuals on the <u>ICES Public Advisory Council</u>. This report was actively written with four Public Advisory Council members, but authors wish to thank the entire council (past and present) for their partnership on this project:

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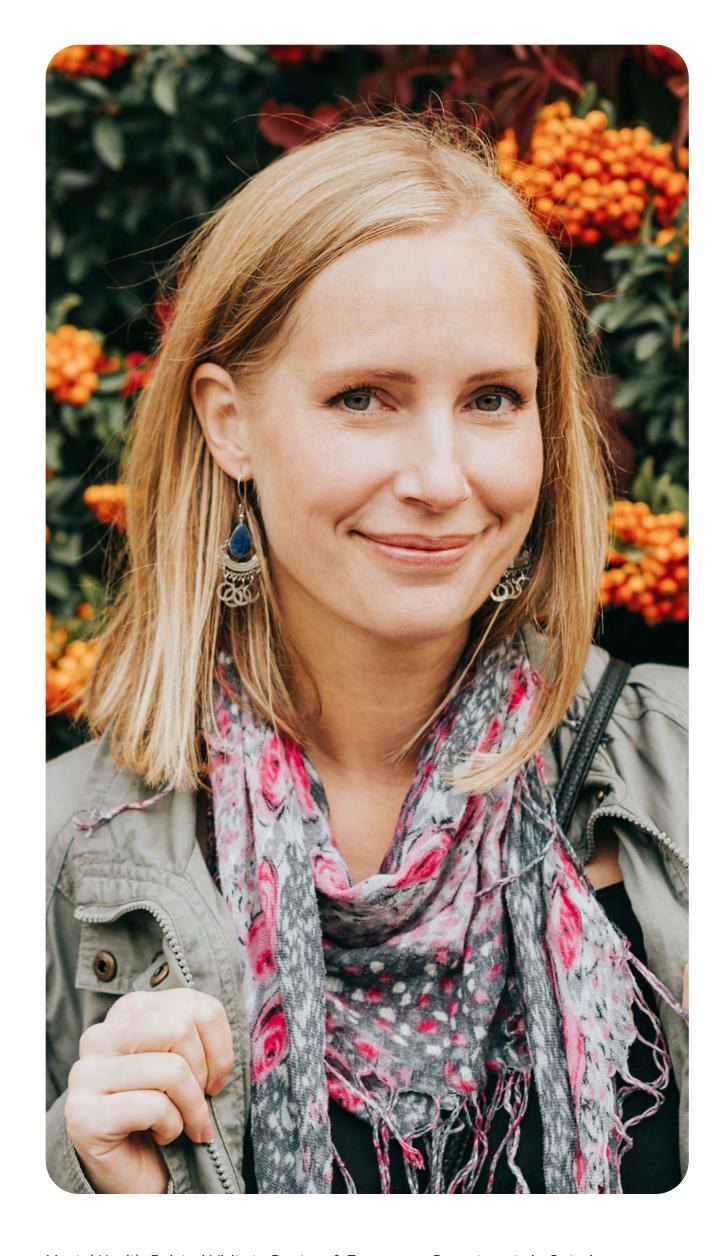


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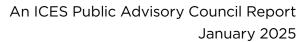
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The ICES Public Advisory Council (PAC) partnered with the ICES Applied Health Research Question (AHRQ) program to explore patterns in Ontario's population-level health data. PAC members wanted to find out how people use mental health services based on where they live, their income and other social factors. It's rare for members of the public to play a lead role in analyses with large datasets, but PAC guidance added value at every stage of this analysis project¹.

Through full participation in this project, the ICES PAC showed that public perspectives can add value at many different time points in project development and shed light on issues that may not be well understood by researchers.

1 ICES supports analytic projects requested by health system stakeholders under the Ontario Ministry of Health's Applied Health Research Program (AHRQ). This program funds ICES to undertake analyses on behalf of an approved knowledge user, which traditionally has been government and health agencies, hospitals, and public health organizations. Although the PAC is not considered a traditional knowledge user group, providing the public with decision-making power and better access to

data through structures like the AHRQ program are priorities for ICES and support-

There were multiple lessons learned throughout this project, including:

- 1. Use multiple public engagement approaches suitable for different stages of the project lifecycle.
- 2. Form a **dedicated team and supportive organizational structures** to promote buy-in and maintain accountability.
- 3. Hold public interest and engagement via **sustained communication**, a transparent and flexible timeline and real-time responsiveness to process feedback.
- 4. **Share power** to build trust.
- 5. Make space for public insight during data interpretation and analysis.
- 6. Carefully consider the need for "diversity" vs "representation."

Findings highlight differences in mental health service use after the onset of the COVID-19 pandemic by **neighbourhood income**, **material resources** and **housing stability**. In early 2022, people living in neighbourhoods where these factors are at their lowest levels visited both doctors and emergency departments more than people living in neighbourhoods where these factors are at their highest levels. The difference in doctor visits between these neighbourhoods was small to moderate, but the difference in emergency department visits was more pronounced (almost three times as often).

These findings add to the existing literature of how social factors affect mental health service use.

Service use changed **over time**. For example, there were fewer emergency department visits for mental health concerns at the onset of the COVID-19 pandemic, and Ontarians more frequently visited a doctor for help with mental health-related issues during this period, often by phone or computer, and primarily for anxiety and depression-related issues.

Service use also differed based on where people lived. People living in Toronto visited doctors for mental health services more frequently than elsewhere, while those living in Northern Ontario were the most frequent visitors to the emergency department for mental health. Some PAC members speculated that greater reliance on emergency departments may be due to a family doctor shortage in the North.

In line with their values of Equity and Access, the PAC felt that these findings should be discussed with decision makers to inform future programs, policies, infrastructure and resourcing. This may improve the health care experiences and quality of life of Ontarians. The practical strategies and lessons learned from this project can guide public partnership for future projects at ICES and beyond as well as help improve trust, acceptance and interest in other initiatives using population-level health data.





ed by the Ministry of Health.



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Background

The ICES Public Advisory Council members expressed a desire to become more directly involved with an analysis project. The objectives of the project were to improve public knowledge, engagement and collaboration.



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This report outlines the process, results and lessons learned from a public-led analysis of mental health service use in Ontario. The analyses for this report were conducted at ICES using administrative health data and guided by the ICES Public Advisory Council (PAC), in partnership with the Applied Health Research Question (AHRQ) program. Since 2019, the PAC has provided a public voice in corporate-level activities at ICES and scientist-led projects. The PAC comprises members of the public from across Ontario and reflects a range of geographic locations, ages, abilities, races, gender identities, and health care experiences. Council members often have lived experience with health and social conditions as patients or caregivers.

In 2020, PAC members expressed a desire to become more directly involved with **project-level activities**, including contributing to an AHRQ project. The ICES' AHRQ program enables health system stakeholders to request data and analytics that help inform improvements in services or policies. Eligible organizations often include institutions such as hospitals, government ministries and Public Health Units. They can also include community-based organizations such as local non-profits, provincial associations and community health centres. However, providing the public, for example the PAC, with decision-making power in research and better access to data through structures like the AHRQ program are priorities for ICES and supported by the Ministry of Health (MOH).

This structure also reflects committed actions from the equity-centred approach detailed in the <u>Guidance Document</u> and <u>Framework for Anti-Racist Approaches to Research and Analytics at ICES</u>.

The original goal of the PAC's AHRQ project was to improve public knowledge, engagement and collaboration. The objectives were as follows:

- To respond to the public's interests and priorities for health data analysis.
- To engage and inform PAC members on how ICES uses routinely collected health data to generate evidence to improve health policy and planning.
- To demonstrate transparency around the use of public funding under the AHRQ program and empower the PAC to lead the development of an analysis question.
- To guide PAC members through data interpretation and the creation of knowledge products that are accessible to the public.
- To inspire future public-led analyses at ICES and beyond.

The project began during the height of the COVID-19 pandemic when mental health was top of mind for researchers, health care providers and the public. The PAC considered many different topics, but none with as much meaning and significance to members as the topic of mental health and addictions (MHA). Ultimately, it was the PAC's interest and personal experience of the topic that solidified MHA service use as a key area to explore in this AHRQ.

This document explores both how we worked together (process) and what we learned together (findings).







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How We Worked Together

"The ICES team welcomed PAC member feedback in both public and private settings so that everyone's feedback was taken into account, even when members were not comfortable giving the feedback in a group setting, or when members missed meetings."

- PAC member



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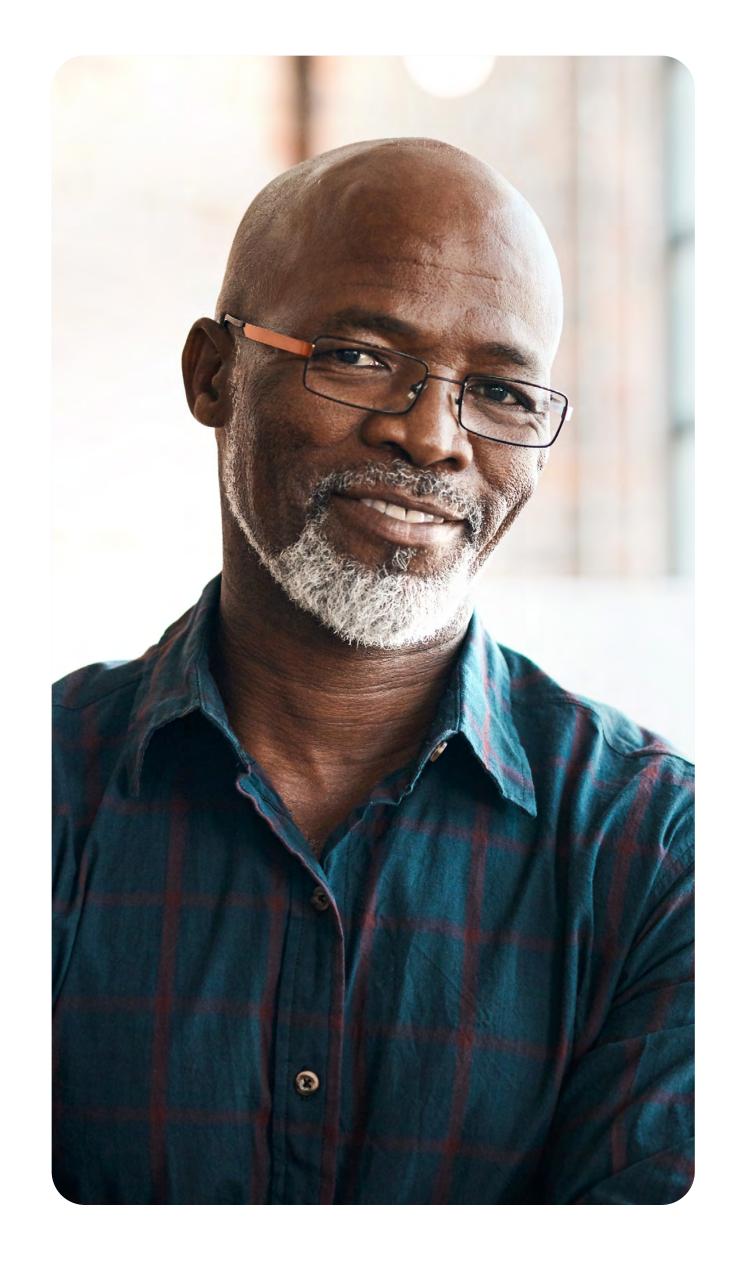
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Our approach is in line with what the International Association for Public Participation describes as engagement at an "empower" level ("we will implement what you decide").¹ This differs in terms of power-sharing from the more commonly practiced "consult" level of engagement ("we will listen to and acknowledge your concerns and aspirations").¹

A plan-do-study-act cycle was embedded throughout the project to continuously monitor, evaluate, pivot and balance the perspectives and decisions of the public and scientists on the team.² An entire overview of the process can be found in <u>Figure 1</u>.

The recurring themes of how we worked together throughout the project include:



Education and Guidance

What does the literature say?

Education and training opportunities support a collaborative process; different content and strategies may increase capacity and participation.³

What was our approach?

The PAC requested two education sessions to support their preparedness and informed decision-making. The first session aimed to orient the PAC to key players, processes and AHRQ examples by:

- Providing an overview of the AHRQ program.
- Making introductions between AHRQ team members and PAC members.
- Reviewing the types of data that ICES has access to.

The second education session supported the refinement of an MHA-related question by describing:

- An overview of the ICES MHA program.
- Examples of past ICES research and AHRQs.
- Limitations and data gaps and how they affect what can be studied.

Three guidebooks were also created that included:

- Examples of past ICES research questions and AHRQs.
- The steps for each part of the prioritization and analysis process.
- A description of the engagement activities and tools for each part of the process.

Materials were provided to the PAC before all sessions to allow for feedback and questions.





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Shared and Guided Brainstorming

What does the literature say?

Balancing power between public contributors and researchers can be a challenge to public engagement in research.⁴ Public members engage more meaningfully when their values are reflected.⁵

What was our approach?

At the PAC's request, the group engaged in a values exercise near the very beginning of the project. The goal was to centre public values throughout the project: Equity, Diversity, Accessibility, Patient Experiences, Health Care Costs, Social Determinants of Health, Quality of Life, Health Outcomes and Access to Social Services and Community Supports.

When decisions needed to be made, ICES staff provided facilitative support to help the PAC reach informed decisions by consensus during:

- Two idea-generation (brainstorming) sessions.
- Three feasibility assessments by ICES scientists to determine what was answerable with ICES data holdings, assess for gaps in the data and rule out any duplicated studies.
- Three deliberative sessions to discuss the results of the feasibility assessments.
- One prioritization session to choose the final analysis question.
- Two deliberative sessions to prioritize results for dissemination.



Consensus Building

What does the literature say?

The public is composed of a diverse group of individuals with varied experiences and perspectives. Discourse and dialogue give individuals a chance to see from each other's perspectives, which promotes organic convergence for practical decision-making as a group.⁶

What was our approach?

The Dialogue Technique values coming together to listen to one another and challenge each other. PAC members met to explore diverse perspectives by listening to each other and asking questions.

The Delphi Process was used to reach consensus as a group, mainly when identifying and prioritizing the analysis topic. The Nominal Group Technique was also used to prioritize the analysis topic and, later, to interpret the analysis and prioritize the results for dissemination. This structured approach broke the large PAC into smaller groups. Each group discussed a similar question and worked together to generate, discuss and then vote on ideas.



Feedback and Evaluation

What does the literature say?

Evaluation is a key step in maintaining and improving engagement processes.⁸ Using multiple methods improves rigour.

What was our approach?

Process feedback and evaluation were iterative and focused on PAC members' satisfaction that the project objectives were met; that the engagement style was appropriate; and that their perspectives were heard, considered, and incorporated.

Multiple modalities were used to assess this: observation, feedback during live large and small group sessions, Zoom chat functions, group activities through Microsoft Word live documents and Google Jamboard, emails and online surveys, questionnaires and polls. The ICES team welcomed PAC feedback in both public (at PAC meetings with other members) and private (via email after meetings, or one-on-one evaluations) settings so that everyone's feedback was considered even when members were not comfortable giving the feedback in a group setting or when members missed meetings.





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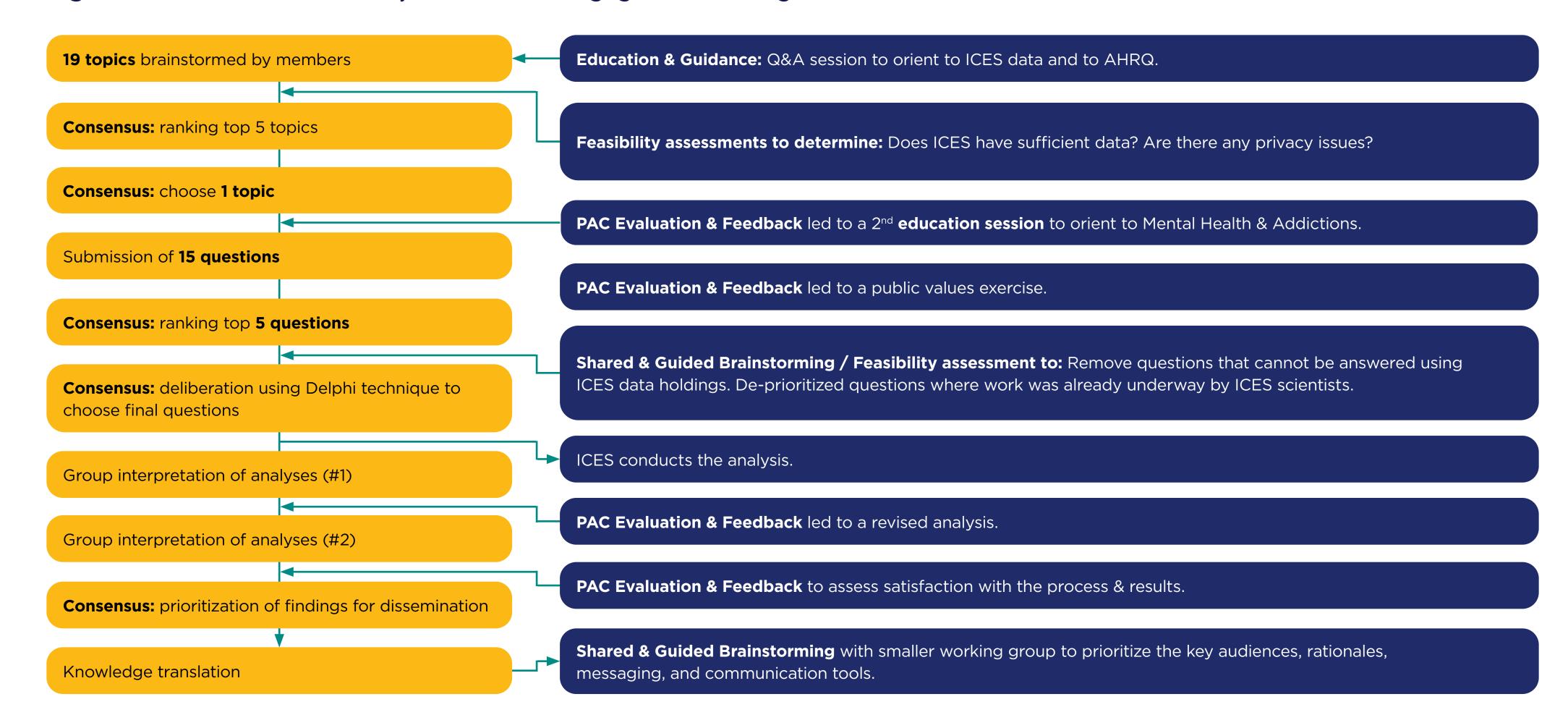
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Figure 1: Process overview: Project roles and engagement strategies







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The Process from Start to Finish

PAC input generated iterative versions of the analysis plan:

"By looking only at outpatient services, we are also likely missing most extreme psychotic episodes (which often end up in the emergency department instead)."

- PAC member



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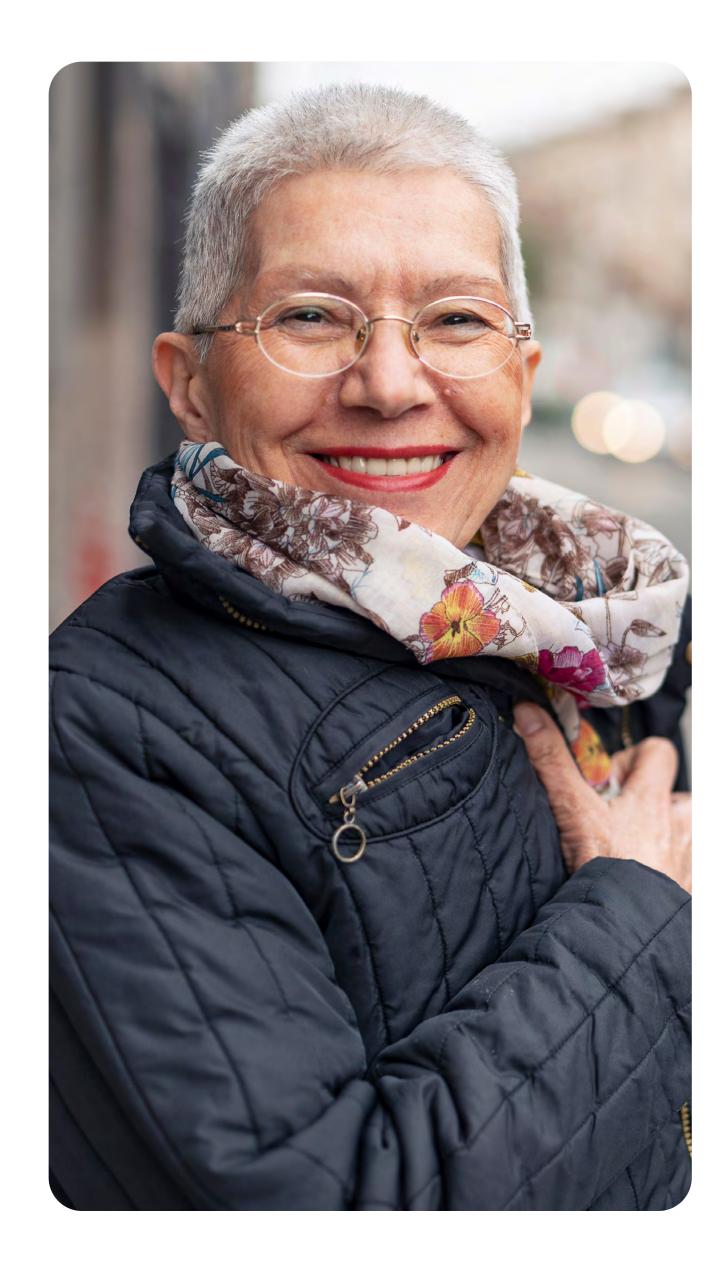
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Step 1: Choosing a topic

In early 2021, the ICES Public and Community Engagement, Knowledge Translation Team and the PAC worked closely to design and develop an analysis topic and question. Each PAC member was invited to submit up to three research topic areas. A total of 19 potential topics were suggested that were determined to be feasible to investigate using the data available at ICES. Each PAC member was then invited to vote for their top five topic areas. After an 80 percent response rate, the cumulative top five topics were deliberated at a subsequent meeting. PAC members then voted for the final topic of *changes in MHA service use over time*.

Step 2: Making an analysis question

Once the broad topic area was chosen, PAC members were invited to suggest more specific questions to investigate. ICES staff assessed these for feasibility, data availability and originality (e.g., whether the same question was already being investigated at ICES).

The James Lind Alliance Framework was adapted to guide this process.⁹ Although a high volume of questions was submitted (between one to three from each member), PAC members also mentioned that they had gaps in their knowledge about ICES data and asked ICES staff to provide an overview of ICES' data holdings to help the PAC refine their research questions (as described above).

These meetings and post-meeting activities included:

- A summary of the submitted research questions that could be answered using ICES data, those that couldn't, and those that would duplicate work already underway
- An opportunity to ask questions of the MHA and AHRQ teams
- A pre-vote ahead of a final consensus-building meeting to help narrow the list of potential questions
- A second meeting with breakout groups for the PAC to discuss the remaining questions and reach consensus after discussion with the MHA and AHRQ teams
- A final post-meeting survey to ensure that members who couldn't attend the prior meetings had an opportunity to vote on the final question.
- Consensus was reached on the question: What are some factors that frequently contribute to outpatient mental health visits?





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Step 3: Understanding the data

Data Analysis Phase I

ICES staff drafted an analysis plan for review and PAC input helped to shape the plan. The final research objectives were agreed to be:

- To quantify mental health-related doctor visits and describe why the visits were made (psychotic disorder, mood/anxiety disorder, substance use and addictions, social problems, and other mental health reasons);
- To examine the time trends in these visits from April 2012 to March 2022; and
- To examine differences in visit rates by sociodemographic characteristics.

Appendix 1 contains more information on the statistical methods and data used in the analysis for this report. The first iteration of data analysis was presented to the PAC for discussion at a half-day meeting in October 2022. After an interactive presentation of the analyses, PAC members were divided into smaller groups to discuss their interpretation of what they were seeing and any questions that came up. Google Jamboard was used to facilitate virtual collaboration at this hybrid meeting (Appendix 2). This process was guided by a semi-structured template with guiding questions for discussion.

Based on the initial shared understanding built during the question development phase, ICES analysts calculated the number of MHA-related doctor visits for a specified period (Appendix 1). However, after viewing the graphs generated from the first round of analysis, PAC members identified the value in including additional analyses pertaining to MHA-related emergency department visits in the objectives (Appendix 2). This input led the PAC to revisit the analysis plan and add analyses that compared doctor visits with emergency department visits.

Data Analysis Phase II

The PAC had a final meeting in February 2023 to review the results of the revised analysis, which included emergency department visits. PAC members were asked to consider which results were most important to share more broadly, with whom the results should be shared and whether the group had any concerns about sharing the results. These questions were asked via live voting, and a follow-up survey allowed all PAC members to submit their final thoughts on which results should be prioritized and included in subsequent presentations or reports.

The PAC voted for the study report to include results on time trends, geographic region, neighbourhood income, neighbourhood material resources, neighbourhood households and dwellings and neighbourhood age and labour force.

However, some PAC members described discomfort with the framing, methodological limitations and potential interpretation of the neighbourhood racialized and newcomer populations dimension (called "ethnic concentration" at the time of the analysis). The details of these concerns are outlined in Appendix 3 and described in the limitations section of this report. PAC members voted for these results to be excluded in any project deliverables, preferring instead that a tailored information sheet be created for ICES scientists describing the concerns (Appendix 3). Similar concerns with the deficitfocused language used to describe the domain had been raised during community consultations conducted by Public Health Ontario and the MAP Centre for Urban Health Solutions, contributing to the dimensions' renaming.¹⁰ However, we have used the original 2021 variable names throughout this report, which were current at the time we completed the analyses.





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Reflecting on the Process

We realized early in the project that the goal was not to turn the public into scientists and not to turn scientists into the public. Both insights were unique and important to driving the work forward.



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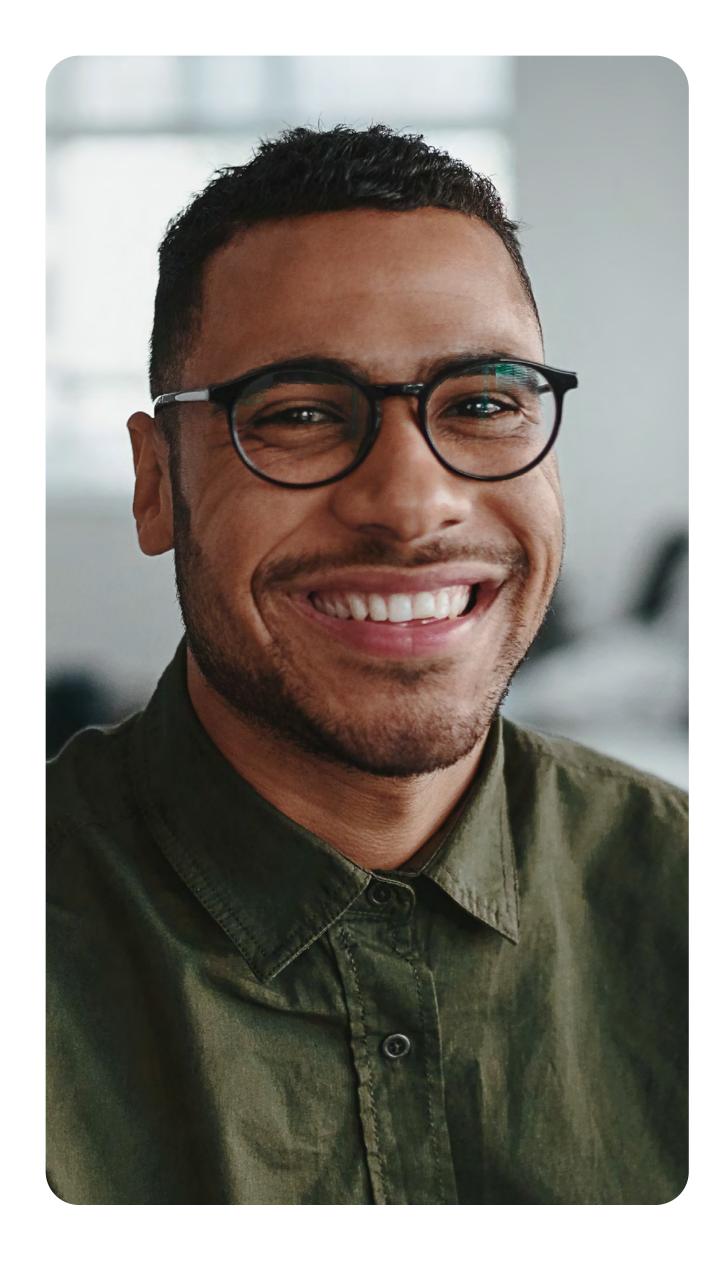
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Increasingly, there is global recognition of the value that a public voice can bring to health research.³ However, there is still much to explore in terms of what public engagement can look like in practice at every stage of the process. The PAC's AHRQ project was a novel undertaking for collaborative analysis between public members and academic researchers using administrative data, and it provided lessons learned that could be built upon for future collaboration.

PAC members suggested key strategies to consider when engaging the public in analyses. ICES staff also offered reflections on lessons learned. Ultimately, we found that there was overlap between the observations, so we summarize the combined reflections below.

I. Use multiple public engagement approaches suitable for different stages of the project lifecycle.

Full integration meant that all PAC members and ICES staff had clear and defined project roles. We realized early in the project that the goal was not to turn the public into scientists or to turn scientists into the public: rather, both insights were unique and important to driving the work forward. Our ways of working together were informed by the PAC and tailored to the goals of different stages of the process. Approaches included education and guidance, deliberative sessions, consensus-building, prioritization and feedback and evaluation (Figure 1).

2. Form a dedicated team and supportive organizational structures to promote buy-in and maintain accountability.

The Public and Community Engagement staff at ICES had existing engagement expertise and a dedicated budget to facilitate this work. The budget included funds to develop project deliverables and appropriate remuneration for participants. By having a dedicated

and consistent team of staff, there was greater opportunity to develop trust among PAC members.

The PAC was also formally attached to ICES with a previously existing (co-developed) Terms of Reference that outlined expectations and defined member commitment as 16 hours per year (quarterly meetings plus work between meetings). This was both a benefit and a challenge, as much of this work may have benefited from more intensive and frequent meetings.

3. Hold public interest and engagement via sustained communication, a transparent and flexible timeline and real-time responsiveness to process feedback.

In this project, PAC members' lived experiences guided discussion in all key project stages. To do this successfully, ICES staff learned about the importance of using plain language in all aspects of the project work to ensure that PAC members could clearly understand what was being presented, what was being asked of them and how their feedback would shape the next stage of the project. For PAC member convenience, all meetings





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PAC Recommendations for Communicating ON-MARG were scheduled well in advance and included an option for virtual attendance. Most of the PAC's discussions on the project were conducted virtually (except two hybrid meetings), which supported participation of PAC members across the province. ICES staff ensured that meeting materials were shared with PAC members in advance and offered different ways to contribute (for example, email versus live dialogue). Not all members liked to participate in large group discussions, preferring instead to contribute after a meeting or in a one-on-one setting. Each member's unique preference was accommodated by offering multiple pathways of engagement: post-meeting online surveys, email, one-on-one phone calls and smaller breakout groups were all offered in addition to the larger (all-member) open forum.

PAC members also had several opportunities to comment on the engagement process, and these suggestions were honoured in real-time. There was follow-up communication on how PAC feedback was implemented to improve the process, which improved overall collaboration and accountability. The ability to shift timelines to accommodate discussion was pivotal because, although evidence-based techniques were used, reaching consensus with a diverse group was time-intensive.

4. Share power to build trust.

Patient engagement occurs along a continuum, starting from lower levels of decision-making influence to higher levels that include decision-making authority.¹¹ This project used collaborative public engagement methods and gave decision-making power to PAC members. For example, a values exercise helped align scientific values with PAC values. Investigative best practices guide all projects at

ICES, but the PAC highlighted the importance of public values/lenses to ensure that quantitative methods address issues that matter to the public (and especially issues that might be affecting the most vulnerable Ontarians). The presence of ICES' senior leadership at all discussions also reinforced ICES' commitment to collaboration and shared decision-making.

5. Make space for public insight during data interpretation and analysis.

Public engagement in administrative data analytics is an emerging area, more common in qualitative research.^{12,13} However, this project demonstrates that public member involvement can add critical insights in this technical phase of work and shed light on things that may not be fully apparent from existing literature or when reviewing the data in isolation. For example, during the project lifecycle, the PAC identified the value of adding data on emergency departments to better contextualize their understanding of the trends and patterns for MHA-related doctor visits. The PAC's emphasis on the methodological limitations of the ethnic diversity dimension of the Ontario Marginalization Index (ON-MARG) also prompted a re-evaluation of the initial results and spurred the development of new guidance for scientists using these data in other projects (Appendix 3).

In addition, involving the PAC in discussions of the quantitative analysis provided an opportunity for the researchers at ICES to get real-time feedback on how they are presenting results to those outside of their own field and whether it can be understood by community members who may be interested (e.g., practice with knowledge translation, removal of jargon, explaining the results in plain

language, simplifying the results, increasing accessibility, etc.). This feedback from the PAC helped reframe results for a wider audience.

6. Carefully consider the need for "diversity" vs "representation."

The PAC aims to reflect the diversity of the Ontario public, with perspectives across geography, age, ability, cultural diversity, education, sexual orientation, gender identity and experience with the health care system. Having a pre-established advisory council supported open dialogue, as rapport and trust between the public partners and the ICES team already existed.

Although diverse opinions brought value to the project, equity experts assert that there are cases where representation is more important than diversity.^{14,15} For an MHA-related project, the most representative public members may be those with lived experience with MHA. However, there were fewer members with lived experience, and a larger proportion of members who may have heard of these issues or had experience indirectly through friends or family. There would certainly have been even greater insights gleaned from an advisory council entirely composed of those with lived experience in Mental Health, however, the diversity of that group may have been more diluted. One PAC member stated that "within a 'majority' of the general public, 'minorities' are still marginalized" which emphasizes the importance of considering what voices need to be reflected by public partners contributing to the project.







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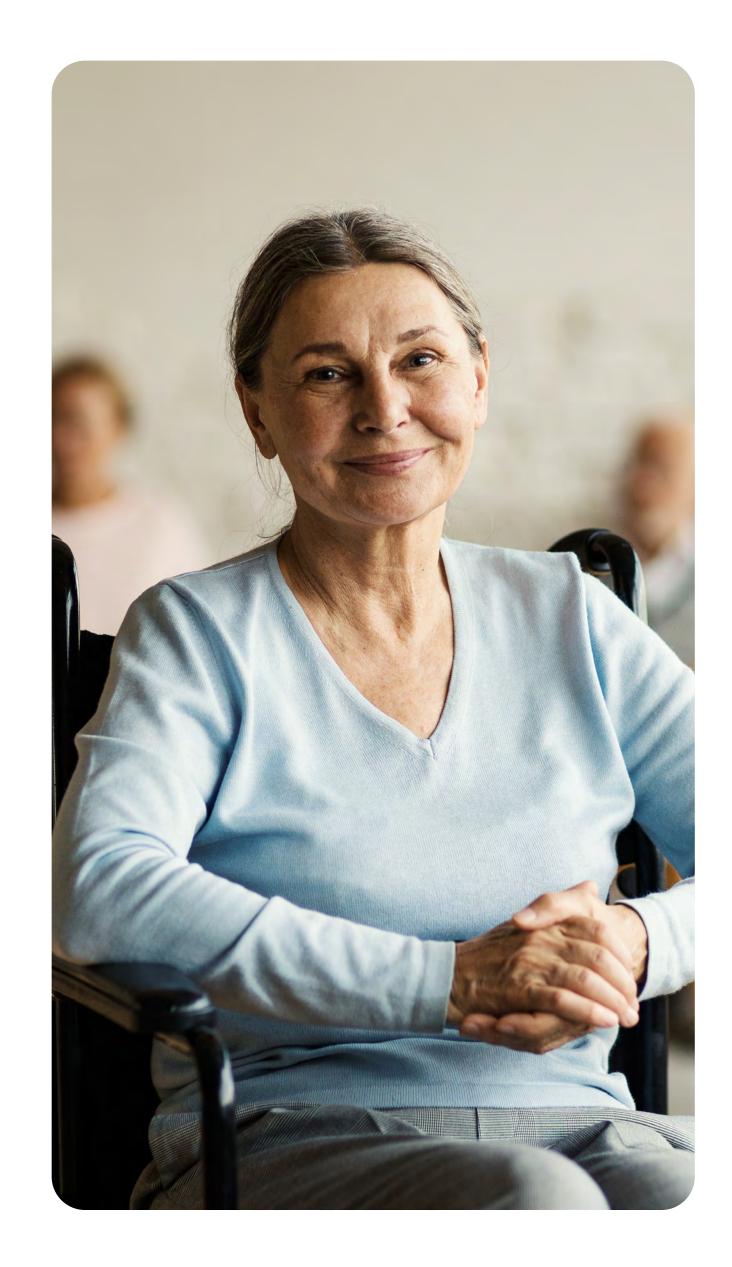
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Process Limitations and Areas for Improvement

This project was the first of its kind for the ICES PAC. Both PAC members and ICES staff identified limitations and areas for improvement.

Firstly, the data analyzed included visits up to March 2022. Updated data may reveal different trends than what is currently reflected in this report or overall changes in patterns of emergency department use across diagnostic groups. In addition, these data are unique to Ontario and may not be generalizable to broader settings in Canada or internationally.

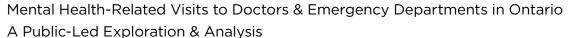
These data measured service use (not need for or access to service). For instance, fewer doctor visits don't necessarily indicate less need for care; it could instead reflect poorer access to care and unmet need. Since the data analyzed in this report do not capture non-OHIP or non-doctor services (e.g., visiting nurse practitioners, private clinics, community health centres, etc.), fewer doctor visits could also reflect that care is being accessed elsewhere. We are not able to examine these gaps using the data available at ICES.

The ON-MARG was used to assign recipients of care into quintiles based on neighbourhood-level measures.¹⁰

These include:

- Material resources: reflects wealth or poverty more holistically than income alone
- Households and dwellings: reflects housing situation in a neighbourhood
- Age and labour force: reflects neighbourhood employment participation







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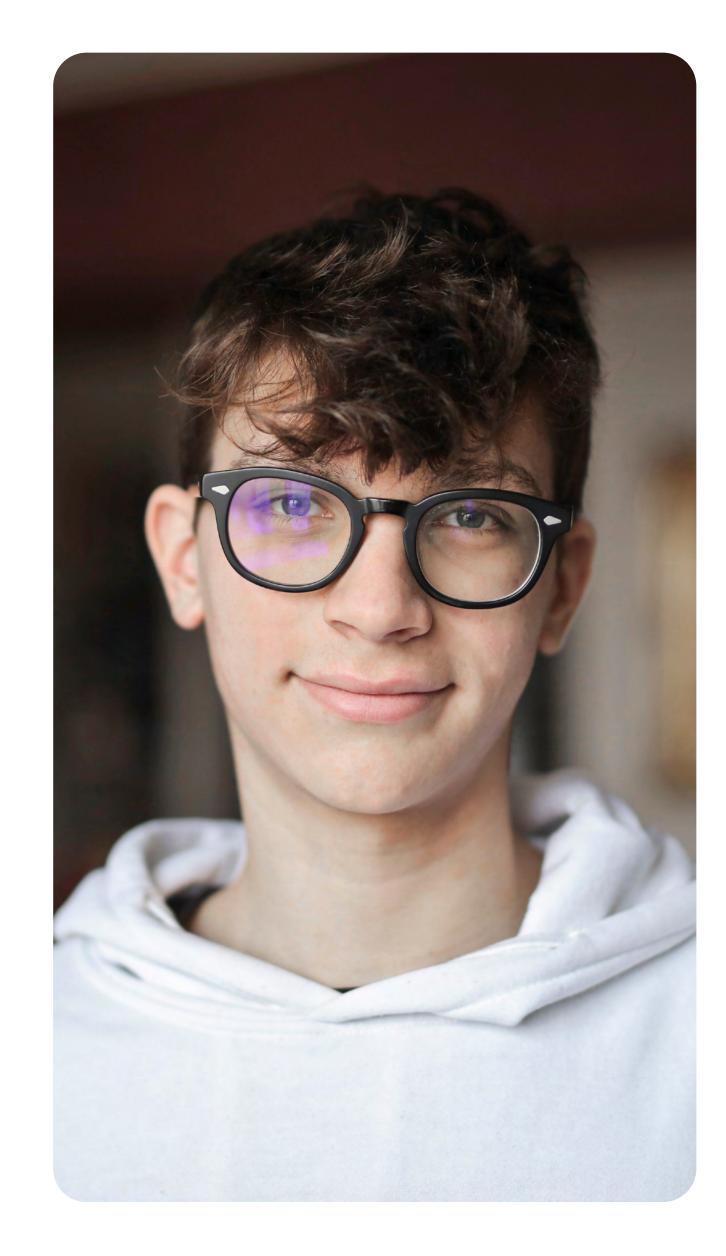
PAC Recommendations for Communicating ON-MARG Detailed descriptions of the ON-MARG can be found elsewhere. The ON-MARG can also include a measure of racialized and newcomer populations (previously called "ethnic concentration"), but the PAC felt that this did not accurately represent the unique nuances of distinct communities. Some PAC members felt this measure may not be an appropriate snapshot of what is happening and we chose to exclude it from our products and report. In its place, a memo was created for staff and scientists noting some of the PAC's concerns on the measure (Appendix 3).

We analyzed the other neighbourhood-level factors in isolation. This means that we examined whether each factor (on its own) is associated with MHA service use. We did not explore associations when these factors are taken together nor interactions among the factors. There are also many other factors (not reviewed in this project) that can influence mental health service use, including how severe the mental health challenge is and what service is closest to someone. Neighbourhood-level measures also may not accurately reflect the characteristics of all individuals living within that area. For example, an individual person may have a higher income and still live in a neighbourhood where many others have a lower income. That said, neighbourhood-level measures have been shown to generally correlate well with individual-level measures (and may also more holistically reflect unmeasured factors that contribute to the experience of living in a given neighbourhood).

In terms of the integrated engagement process itself, we acknowledge that a 20-person PAC cannot represent the views and perceptions of all Ontarians. However, our PAC is recruited to reflect diversity in experiences, ages, gender, location and racial identities. The membership of the PAC also changed in the middle of this project (as per the preplanned three-year term change), meaning that 42 unique individual members were involved in some way. Although allowing for new members broadened insights, better continuity may have supported a more consistent vision and evaluation for the project.

Some specific engagement activities were not successful on the initial attempt. For example, to achieve consensus, open discussion sometimes had to be repeated either using online surveys or by holding another meeting. As in any working relationship, how ICES staff collaborate with PAC members is growing iteratively, and we were fortunate in this project to be able to flex timelines as needed. For future projects, ICES staff will plan to equip the public with the appropriate background information at project onset and build in more time in the initial plan for group discourse to allow adequate room for learning and consensus-building.

Finally, we recognize that an evaluation framework that incorporates more formal engagement, such as that described by Staniszewska et al. could add more rigour to our methods. Due to the iterative nature of our working relationship for this project, evaluation was primarily qualitative and process oriented.







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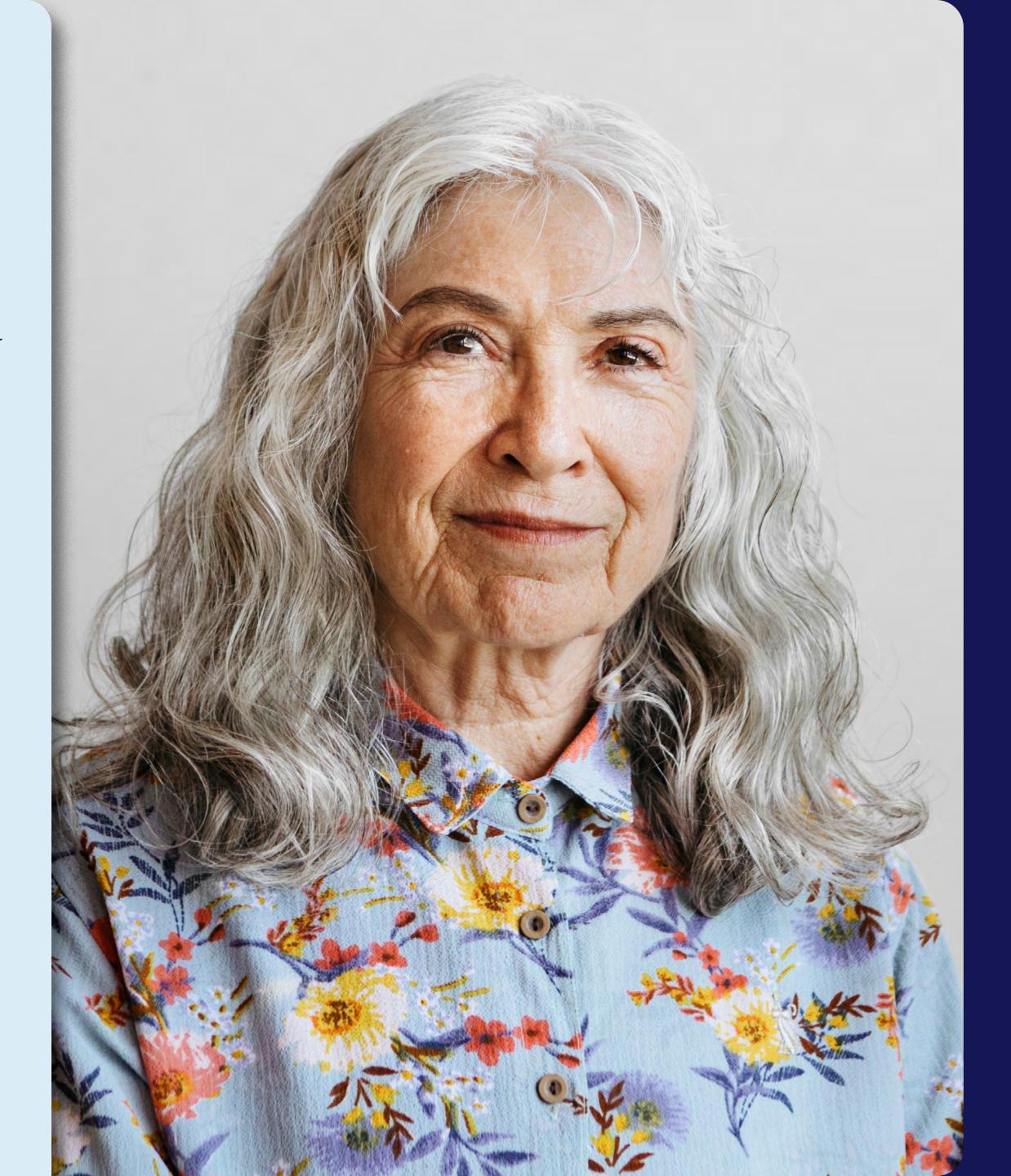
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What We Uncovered in the Analysis Together

Both the Public Advisory Council and Mental Health & Addictions team at ICES acknowledged that the reasons for mental health doctor visits and trends over time are not frequently reported and would be worthwhile to explore.



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The ICES PAC had anecdotal knowledge of the state of mental health care in Ontario, but they were curious about how frequent doctor visits occurred for different mental health conditions and across different groups of people (e.g., Northern vs Southern Ontario, lower income, etc.). Therefore, the chosen analysis question, "What was the most frequent cause for mental health doctor visits (over time)?" was deemed the most important for the group to explore.

Both the PAC and MHA teams at ICES acknowledged that the reasons for mental health doctor visits and trends over time are not frequently reported and would be worthwhile to explore. The onset of the pandemic saw an initial large and rapid decline in mental health care utilization in Ontario, followed by a sustained increase above expected levels.¹⁷ Variation in service use by geographic region, neighbourhood income and other factors were observed pre-pandemic.^{18,19} It was not known if these trends persisted throughout the pandemic.

It's important to note that measuring who *uses* care doesn't directly measure who needs care.²⁰ For example, past ICES work has observed a strong relationship between psychiatrist supply and service use, but a mismatch between psychiatrist supply and population needs.²¹ However, as noted in the 2021 ICES Mental Health Report,²² understanding variation in use of services can point to gaps and inequities in access to service.





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Summary of Exhibits

Exhibit 1. Rates of mental health-related visits over time »

- A. Doctor visits between April 2012 and March 2022
- B. Emergency department visits between April 2012 and March 2022

Exhibit 1 shows a) the number of people visiting their doctor and b) visiting the emergency department for different mental health-related reasons over a period of time, including before the COVID-19 pandemic and the period following the onset of COVID-19.

Exhibit 2. Rates of mental health-related visits by neighbourhood income »

- A. Doctor visits between January and March 2022
- B. Emergency department visits between January and March 2022

Exhibit 2 shows a) the number of people visiting their doctor and b) visiting the emergency department for different mental health-related reasons based on neighbourhood income level.

Exhibit 3. Rates of mental health-related visits by neighbourhood material resources »

- A. Doctor visits between January and March 2022
- B. Emergency department visits between January and March 2022

Exhibit 3 shows a) the number of people visiting their doctor and b) visiting the emergency department for different mental health-related reasons based on neighbourhood material resources. Material resources reflect wealth or poverty more holistically than income alone.

Exhibit 4. Rates of mental health-related visits by neighbourhood households & dwellings >>

- A. Doctor visits between January and March 2022
- B. Emergency department visits between January and March 2022

Exhibit 4 shows a) the number of people visiting their doctor and b) visiting the emergency department for different mental health-related reasons based on neighbourhood household situation. Household and dwelling situation reflects housing stability in a neighbourhood.

Exhibit 5. Rates of mental health-related visits by neighbourhood age & labour force >>

- A. Doctor visits between January and March 2022
- B. Emergency department visits between January and March 2022

Exhibit 5 shows a) the number of people visiting their doctor and b) visiting the emergency department for different mental health-related reasons based on neighbourhood age and labour force groups. Age and labour force is related to neighbourhood employment participation.

Exhibit 6. Rates of mental health-related visits between regions »

- A. Doctor visits between January and March 2022
- B. Emergency department visits between January and March 2022

Exhibit 6 shows a) the number of people visiting their doctor and b) visiting the emergency department for different mental health-related reasons based on where they live in Ontario.





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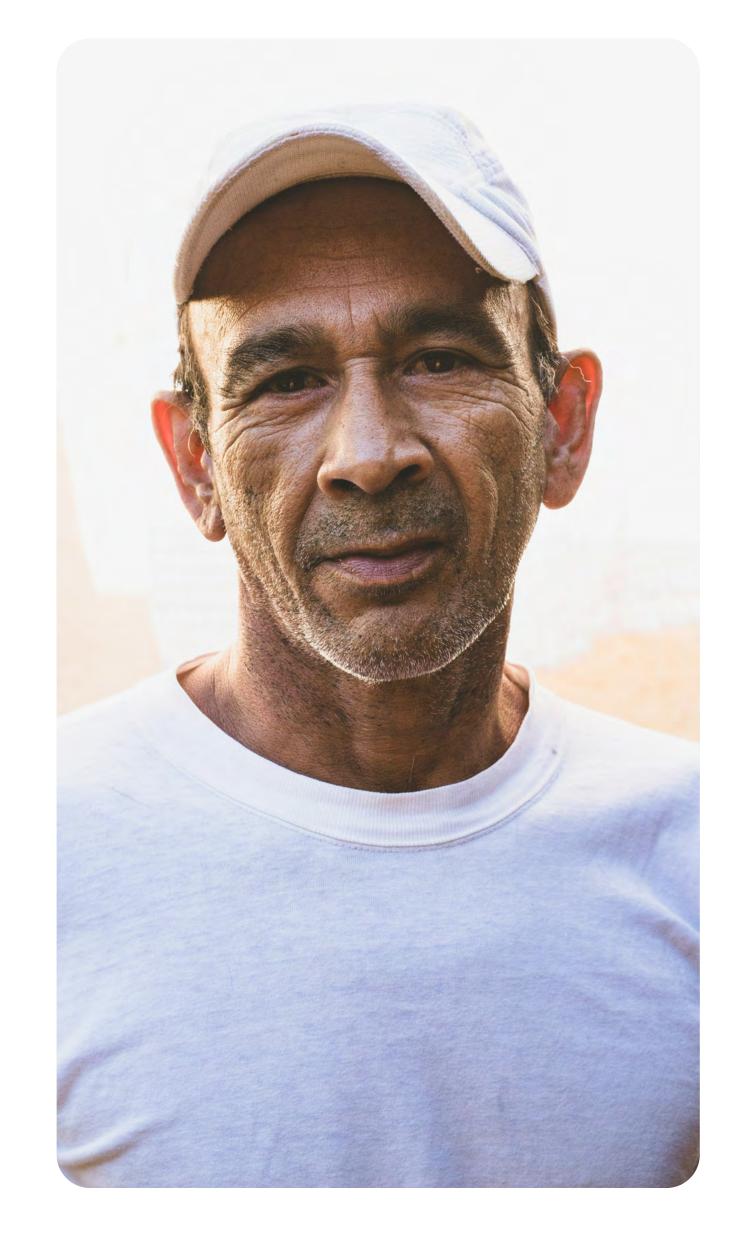
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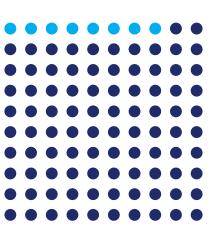
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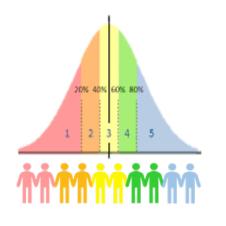
Key Terms

This page provides technical terms you might come across in our findings and exhibits. The terms are listed in the order they appear in the report. Here's what they mean:



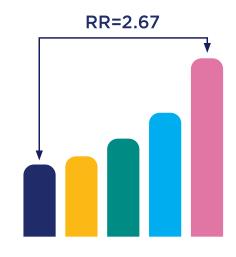
Number of visits per 100 persons: Some graphs show the number of doctors' visits for every 100 persons. For example, there were 8 visits about mood and anxiety for every 100 persons between April and June in 2012. Since 13 million people lived in Ontario, this "8 out of 100" means about 1 million visits happened during those months.

Number of visits per 1,000 persons: Some graphs show the number of emergency department visits for every 1,000 persons. For example, there were 2 visits about mood and anxiety for every 1,000 persons between April and June in 2012. Since 13 million people lived in Ontario, this "2 out of 1,000" means about 26,000 visits happened during those months.



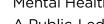
Quintile: Researchers often group data into five quintiles. For example, to sort 10 people into five quintiles by age:

- The two youngest people are in quintile 1
- The next two younger people are in quintile 2
- People with ages in the middle are in quintile 3
- Two older people are in quintile 4
- The two oldest people are in quintile 5



Relative risk: A relative risk (RR) score compares how often something happens in one group of people compared to another group with different characteristics. In our exhibits, this is usually comparing the highest group with the lowest group. We present the relative difference between groups as an RR score.

- A score of exactly 1 (RR = 1) means there is no difference between the two groups.
- A score of 2.67 (R = 2.67) means that something happens almost three times more often in one group than the other.





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Age-standardized rate: People in one region might be older (on average) than people in another region. How do we know that we are looking at differences between people living in different regions instead of differences between people with different ages? An age-standardized rate lets us look only at regional population differences by making ages the same.

Age and labour force: "Age and labour force" is about neighbourhood employment possibilities. Neighbourhoods with more people over 65 and/or under 15 might have the least potential for labour force participation.

Households and dwellings: "Households and dwellings" is about a neighbourhood's homes and the people who live in them. The "most stable" neighbourhoods have more homeowners and people who have lived there for more than five years. The "least stable" neighbourhoods have more apartments, renters and people sharing a home.

Material resources: "Material resources" reflect wealth or poverty more holistically than income alone. Neighbourhoods with the most "material resources" have more people with high incomes, high school diplomas and/or employment. Neighbourhoods with the least "material resources" have more single-parent families and/or unmet home repair needs.





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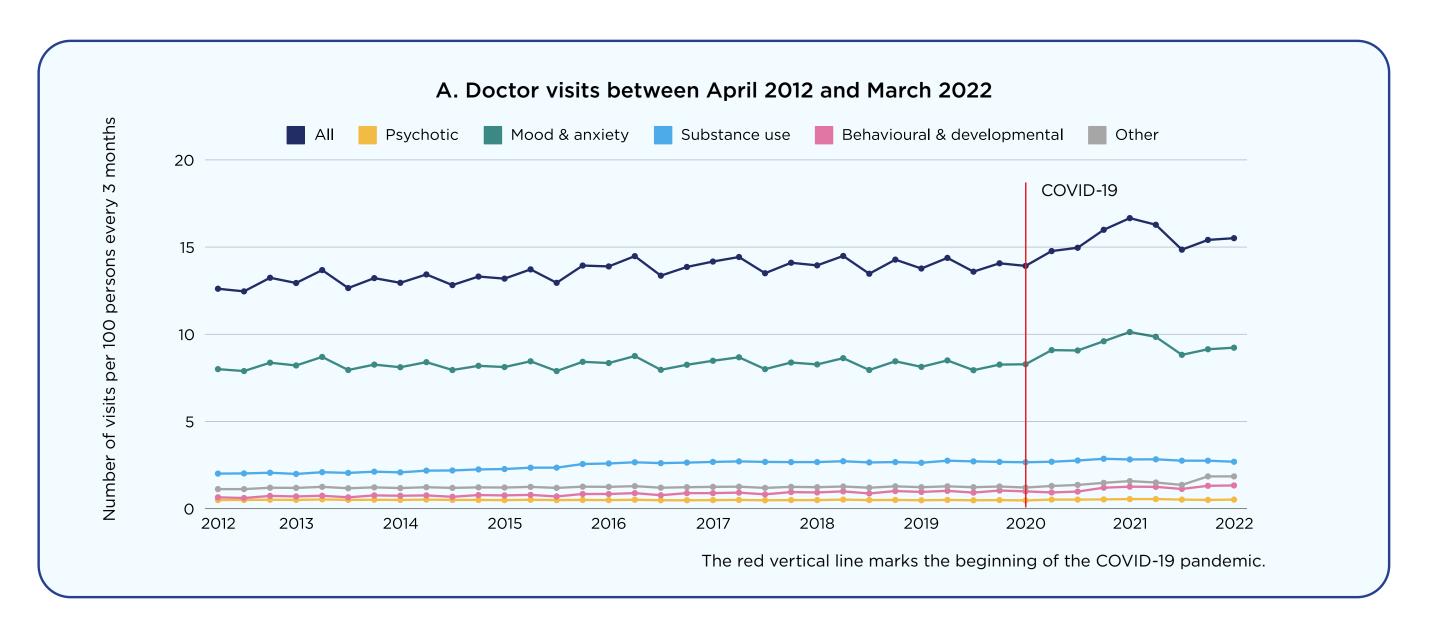
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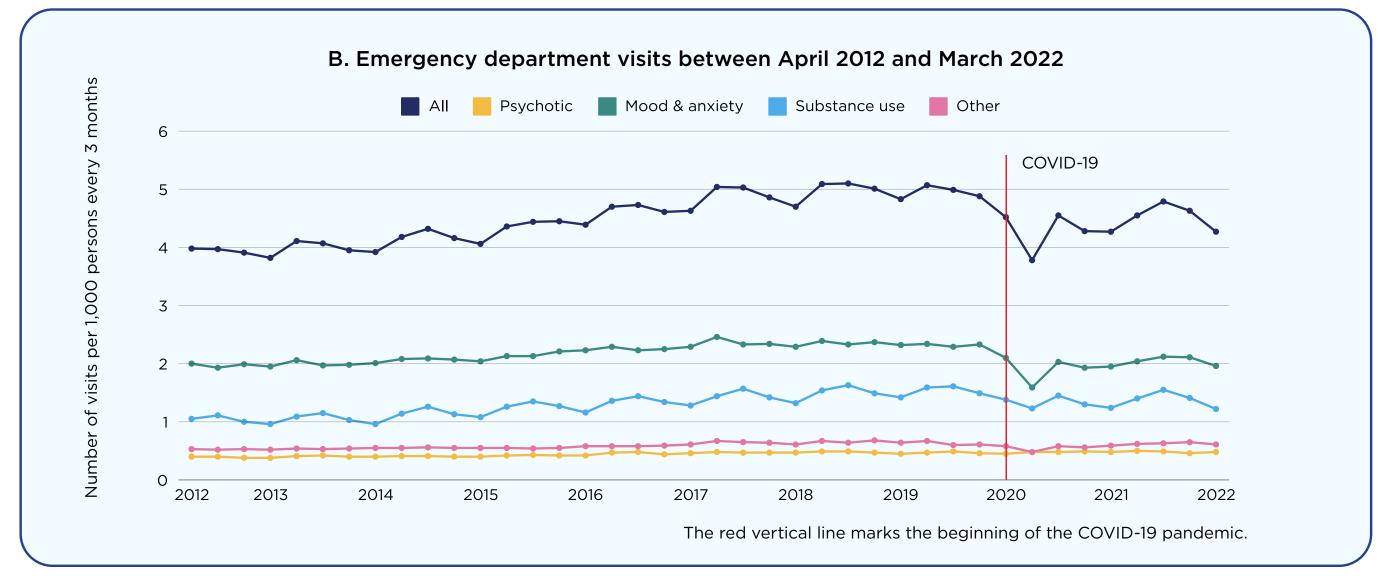
Rates of mental health and addictions-related visits over time

Summary of Findings

At the beginning of the pandemic, Ontarians more frequently visited doctors for MHA-related issues, often by phone or computer. The quarterly number of MHA-related doctor visits jumped from 14.5 to 16.5 visits per 100 persons during the pandemic period. This jump was mainly driven by mood and anxiety disorders like anxiety and depression (the green line) which represented more than half (60–66 percent) of MHA-related doctor visits. Doctor visits for other MHA-related conditions remained steady.

On the other hand, there was a slight decrease in the quarterly number of visits to the emergency department for MHA at the beginning of the pandemic. **Emergency department visits** were mainly driven by **mood and anxiety disorders** (the green line), which represented half of all MHA-related visits. Emergency department visit rates hadn't returned to pre-pandemic levels by the end of our observation period.









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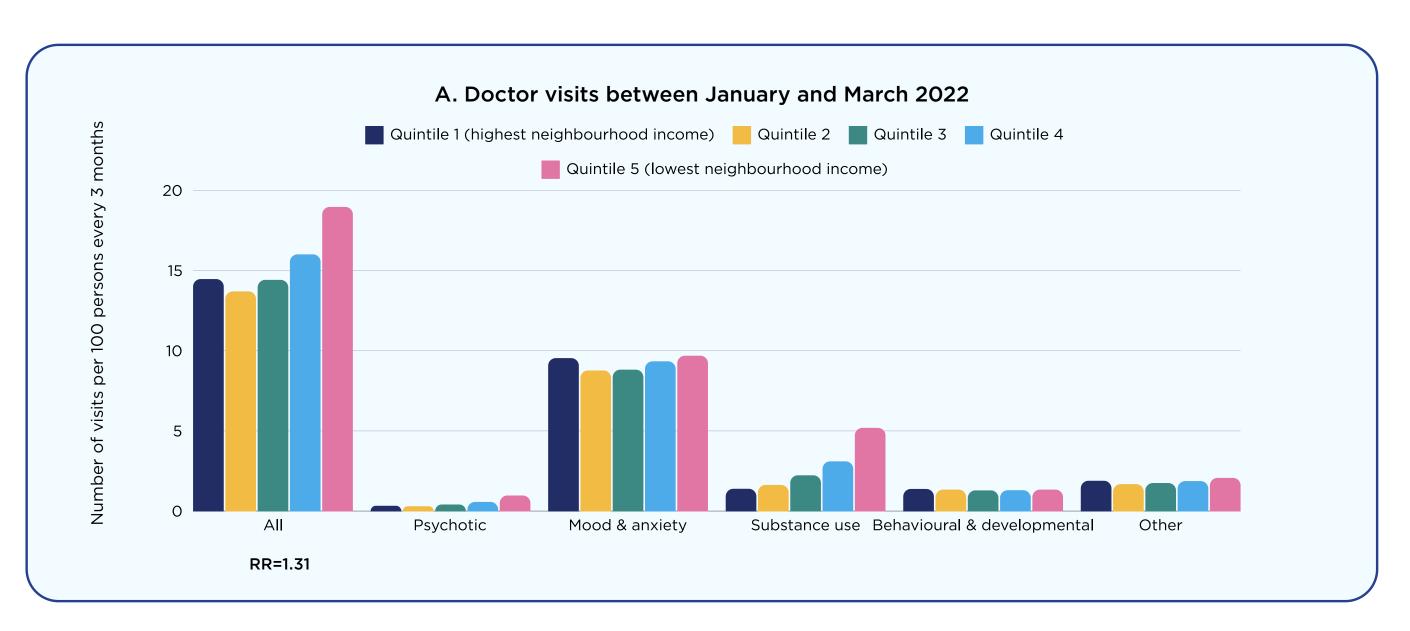
Exhibit 2: Neighbourhood income groups: Rates of mental health and addictionsrelated visits

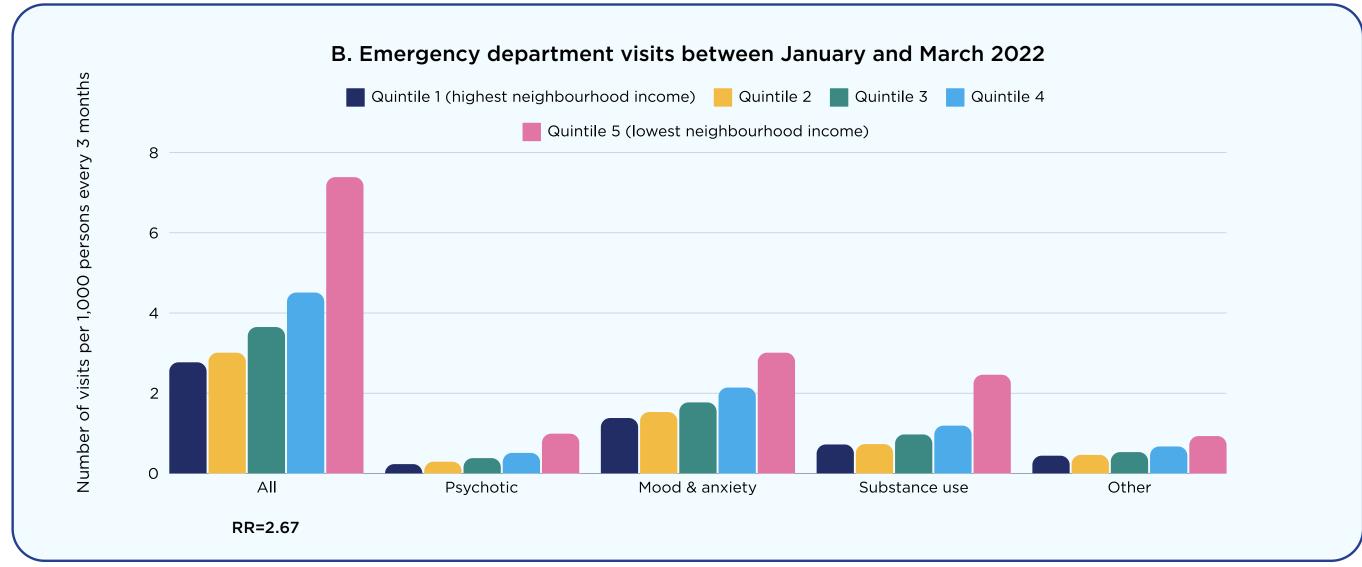
Summary of Findings

People living in neighbourhoods with the lowest income were **more likely to visit doctors** for MHA-related issues when compared to people living in neighbourhoods with the highest income.

Neighbourhood income was found to have more impact on MHA-related visits to **emergency departments**, where people living in neighbourhoods with the lowest income were **nearly three times more likely** to visit than people living in neighbourhoods with the highest income.

Mood and anxiety disorders and substance use account for most of the visits to both doctors and emergency departments across all income quintiles. Still, those living in neighbourhoods with the lowest income may be experiencing more severe mood and anxiety-related health impacts, which need care in the emergency department.









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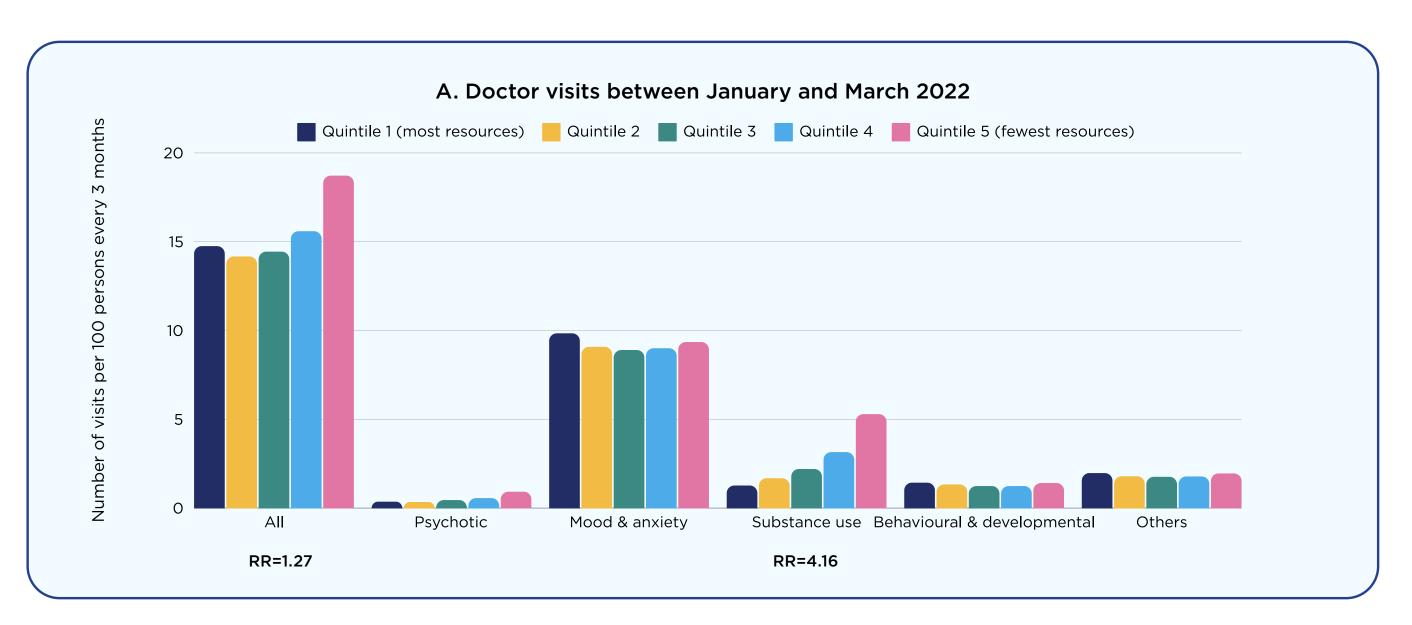
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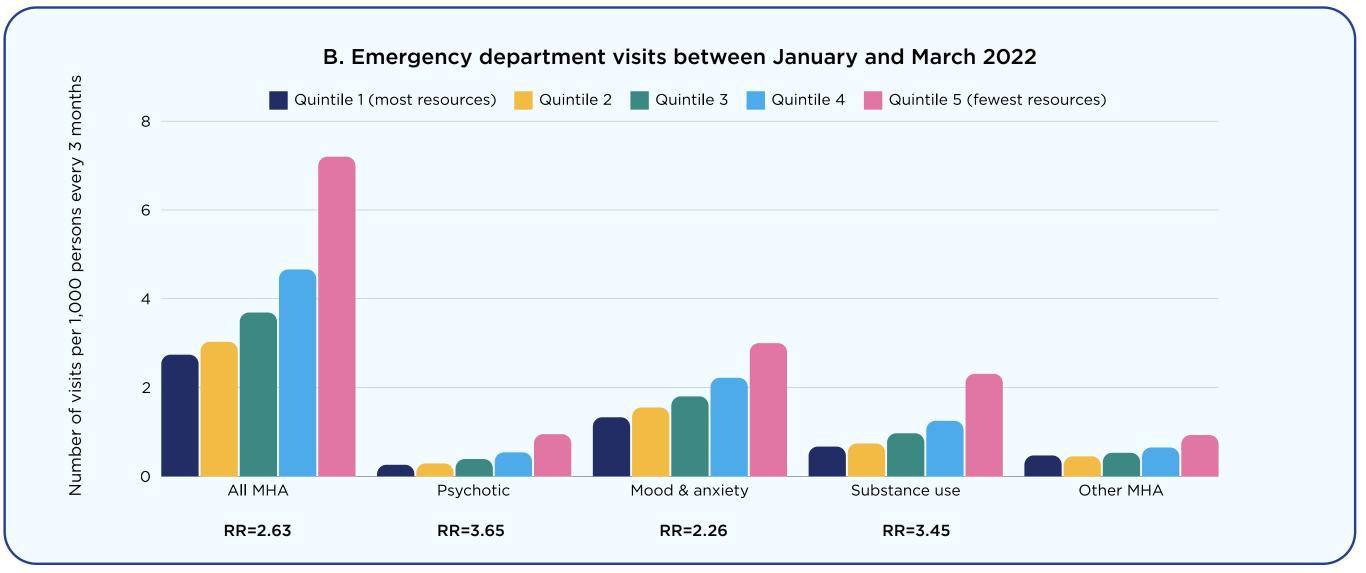
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Exhibit 3: Material resources groups: Rates of mental health and addictionsrelated visits

Summary of Findings

The results for material resources appear similar to the results for neighbourhood income. There were more visits to doctors and emergency departments among those living in neighbourhoods with the fewest material resources compared with those living in neighbourhoods with the most material resources. This impact is larger for visits to the emergency department than doctor visits for MHA-related issues among those living in neighbourhoods with the fewest material resources. Like with income, people living in neighbourhoods with the fewest material resources had a higher number of visits to emergency departments for mood and anxiety disorders, but doctor visits for these disorders were similar across our neighbourhood quintiles of material resources.







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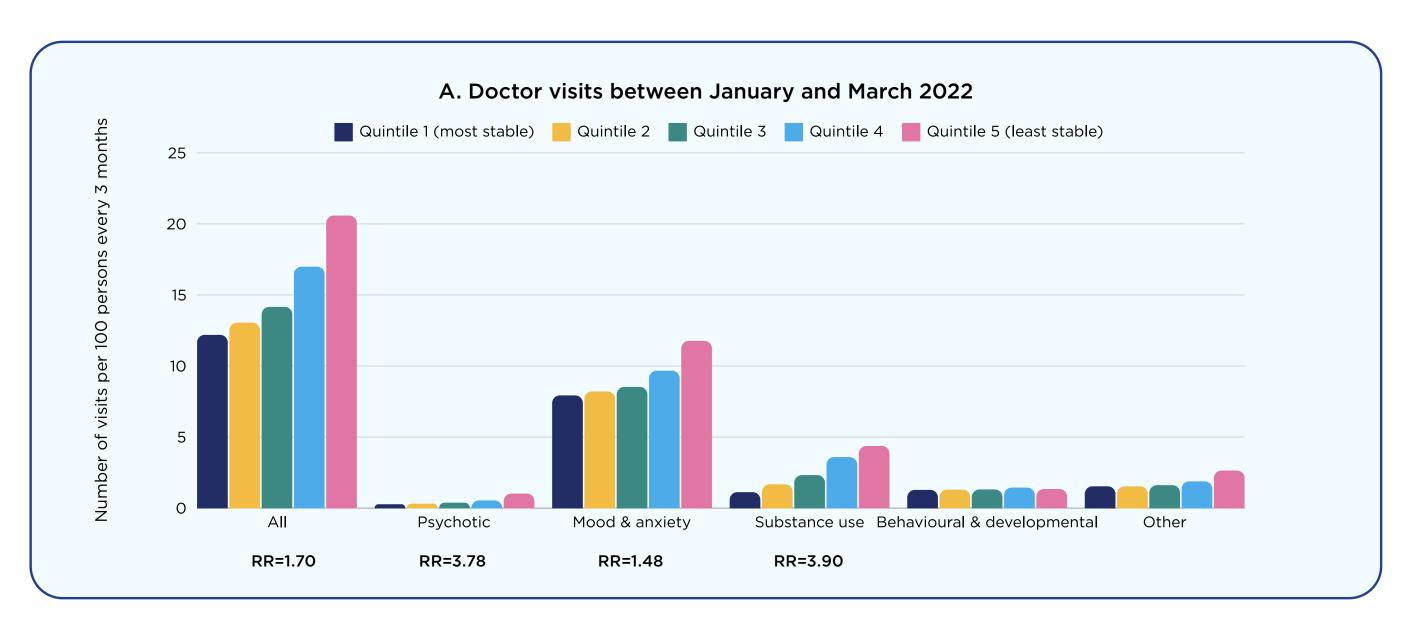
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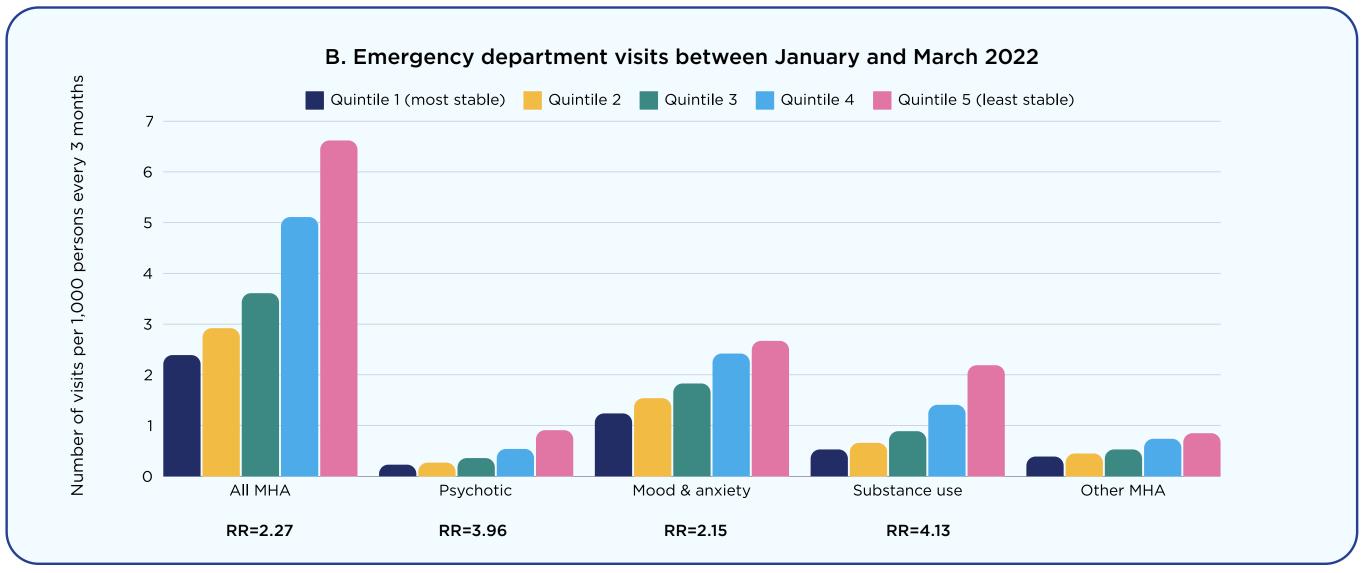
Exhibit 4: Households and dwellings groups: Rates of mental health and addictionsrelated visits

Summary of Findings

People living in the neighbourhoods with the least stable housing situations made **70 percent more doctor visits** for MHA-related issues compared to people living in neighbourhoods with the most stable housing situations. This observed effect of household situation shows a higher impact on visits to the doctor for MHA-related issues than either material resources or income, in particular for mood and anxiety disorders.

The impact of unstable housing on visits to emergency departments is similar to the impact of material resources and income, where people were **three times more likely to visit the emergency department** for MHA-related issues if they lived in neighbourhoods with the least stable housing situations.









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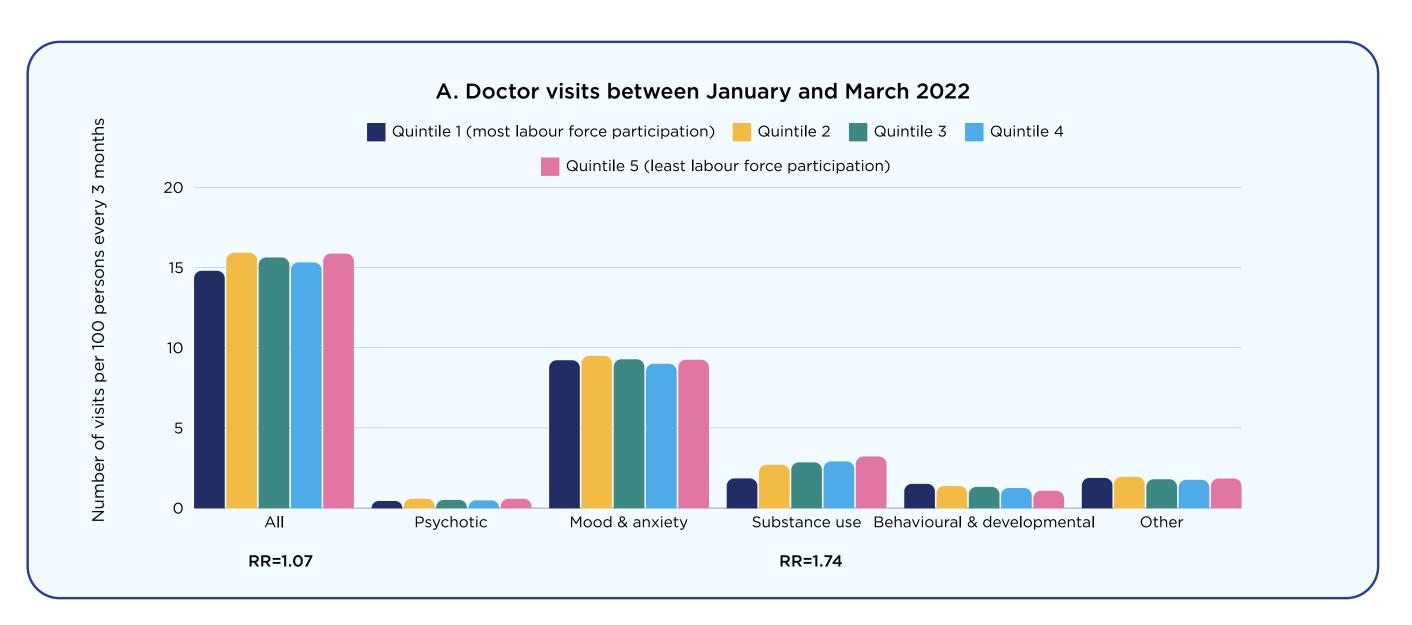
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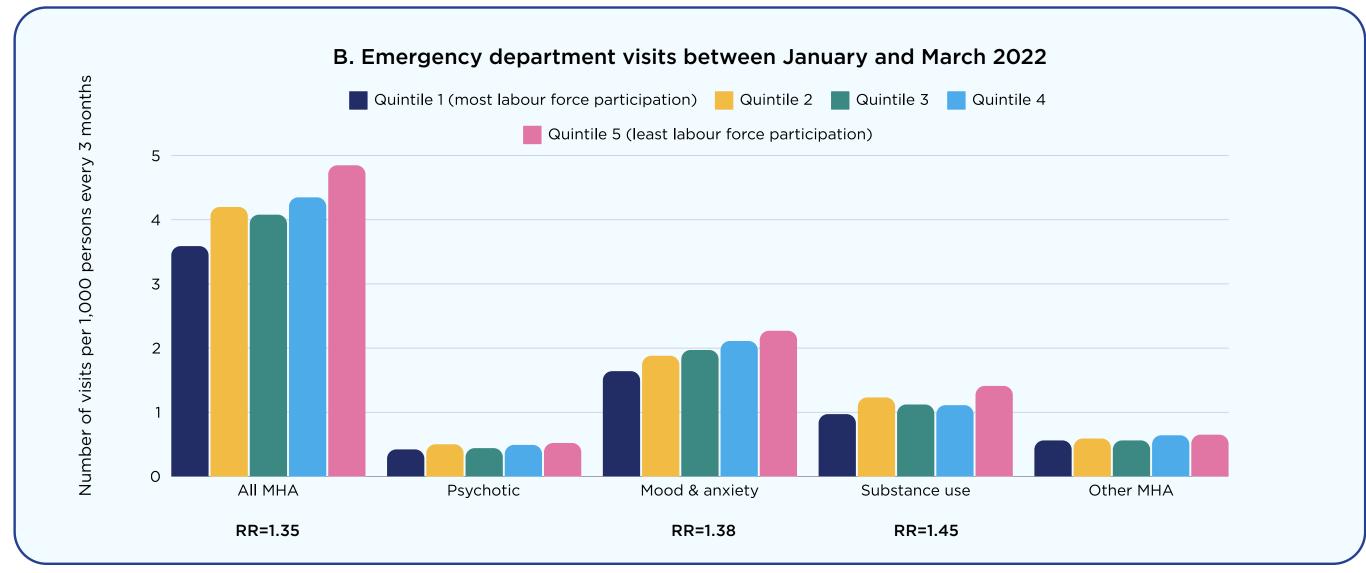
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Exhibit 5: Age and labour force: Rates of mental health and addictionsrelated visits

Summary of Findings

While there is a slight rise in the number of visits to emergency departments by people living in neighbourhoods with the least labour force participation, it does not impact visit rates as much as the previous measures described in Exhibits 2-4 (neighbourhood income, material resources and households and dwellings).









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Exhibit 6: Provincial regions:Rates of mental health and additions-

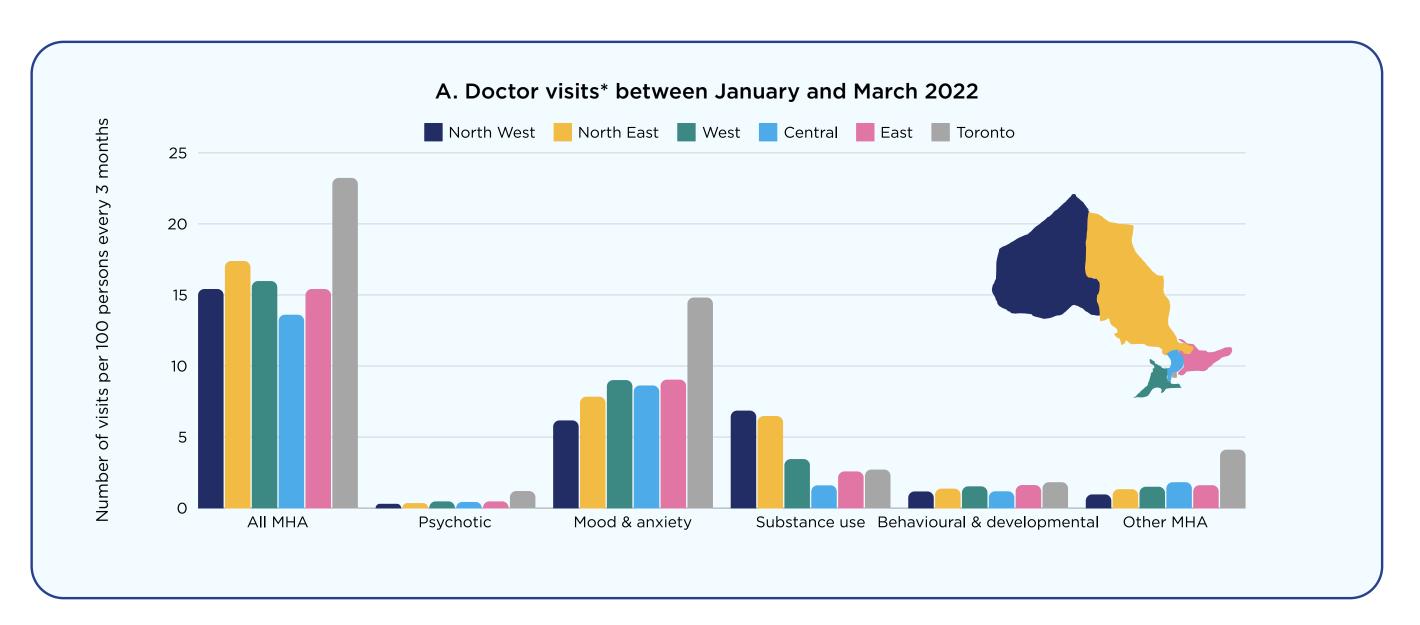
Rates of mental health and additionsrelated visits

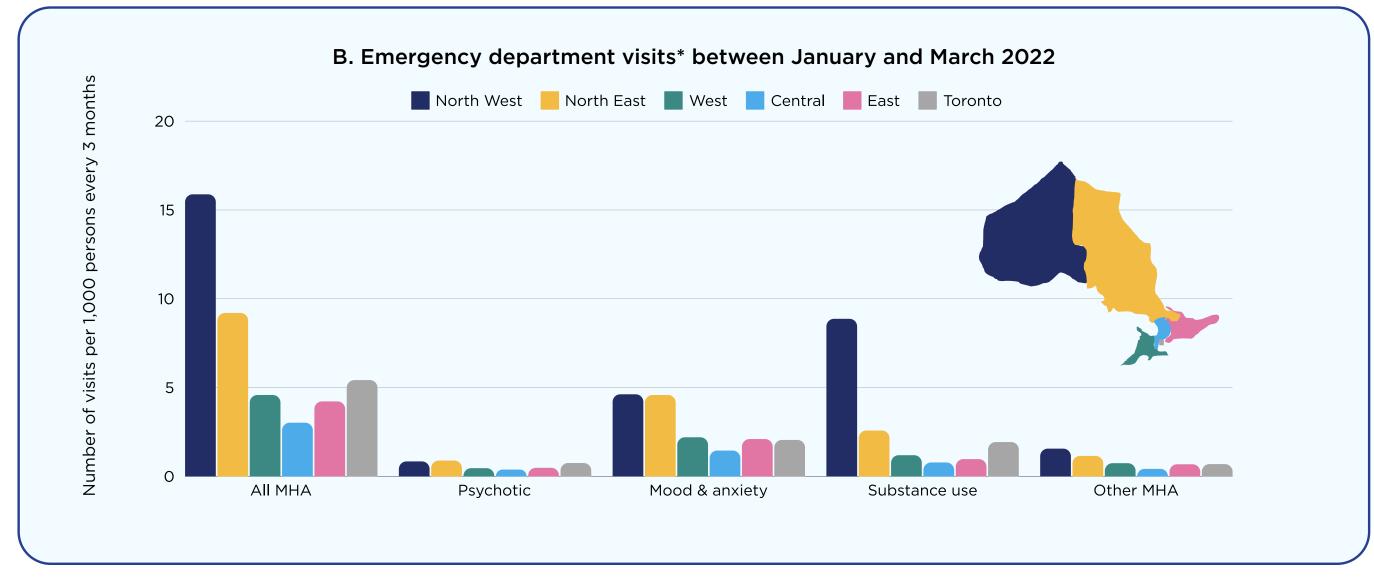
Summary of Findings

There were more **doctor visits** for MHA in **Toronto** (grey bar) than elsewhere in the province. For example, the number of doctor visits was 75 percent higher in Toronto compared with the Central region, which is the area closest in geography and contains Peel, Halton and York regions. **Mood and anxiety disorders** were the most common reason for MHA-related doctor visits in Toronto.

However, this is different for people living in Northern areas of Ontario where there are higher numbers of visits to the emergency department for MHA-related issues than elsewhere in the province. Substance use and mood and anxiety disorders were the most common reasons for visits to the emergency department in the Northern regions. PAC members wondered if lower doctor visit rates in the North may be due to low doctor numbers in these regions; people may be using the emergency department as an alternative.

*The rates and numbers presented here have been age- and sex-standardized based on the 2012 Ontario general population census numbers.









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Reflecting on the Findings

The consensus of the PAC after being presented with the results was that the findings were not only indicative of many issues they had seen firsthand but that they also had important implications for both the public and audiences who could influence change in the mental health system, such as community organizations, services providers, and policymakers.



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PAC Recommendations for Communicating ON-MARG The findings from this analysis support much of the existing literature that recognizes the connection between social factors and MHA service use. Our findings highlight the existing inequities in mental health service use, which may spark important conversations about service access and tailored interventions to address the needs of specific communities.

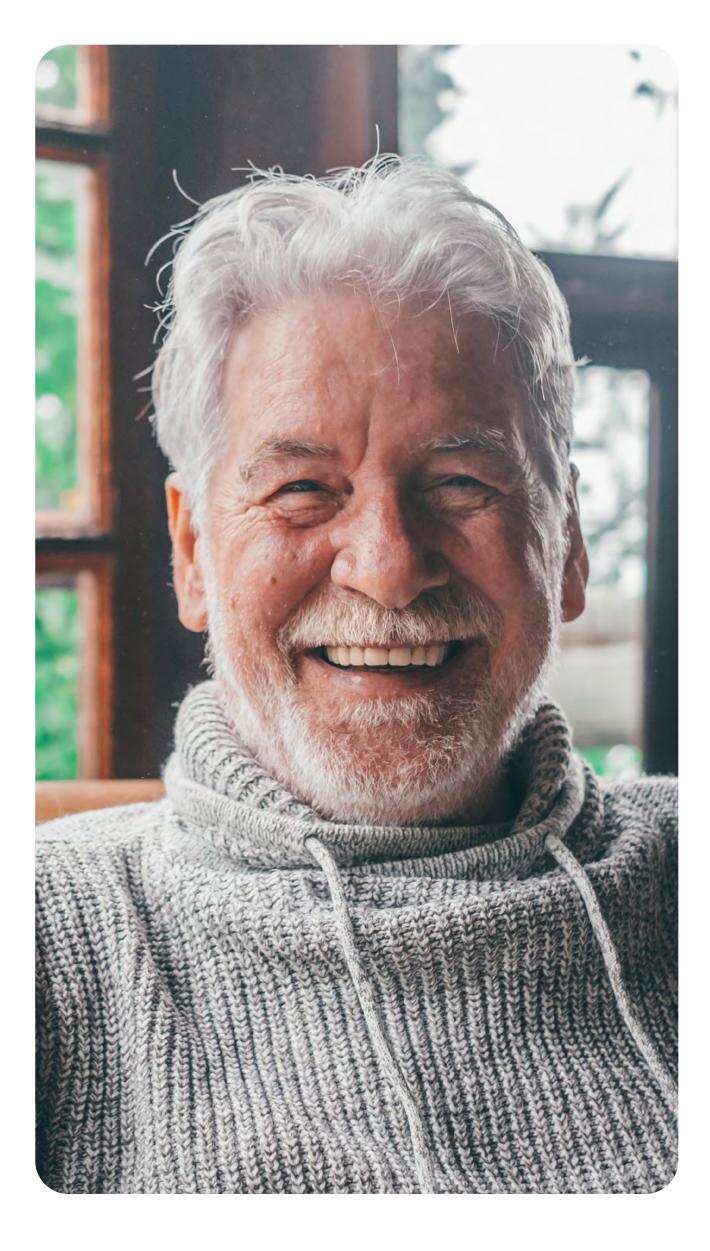
To the members of the ICES PAC, these findings were not surprising but served as a reminder of the importance of understanding regional variations in mental health service use (Exhibit 6). Some PAC members had direct or indirect experience with the mental health system in Northern communities and anecdotally corroborated the results.

Although the PAC did not initially want the focus of this project to be on the COVID-19 pandemic, the results depicting the changes in doctor and emergency department mental health-related visits after the onset of the pandemic piqued their interest (Exhibit 1). PAC members also noted that their own observations from lived experience of the initial dip in emergency department visits at the start of the pandemic matched the trend seen in these data (and across data about other non-MHA conditions).

The consensus of the PAC was that the overall findings spotlight many issues they have seen firsthand and that have important implications. The PAC expressed that these findings should be discussed with audiences who can influence change in the mental health system (such as community organizations, services providers and policymakers) to inform future programs, policies, infrastructure and resourcing. This may be beneficial in improving the health care experiences and quality of life of Ontarians.

Next Steps

Efforts are ongoing to make the findings from this project accessible to the public and key partners (e.g., written in plain language, distributed openly through social media channels) to support uptake and impact (either directly or through further investigation). These products will be made available on the ICES website and through social media but will also be shared through targeted dissemination to key partners and contacts from the PAC and the ICES project team. Ultimately, PAC members highlighted three areas where they hope the findings from this analysis can be used: 1) to increase public awareness about MHA health care use and potential challenges Ontarians could face when accessing care; 2) to advance existing work underway by groups advocating for improved access to comprehensive mental health care; and 3) to identify new opportunities and roles for the public in administrative data research and analyses.







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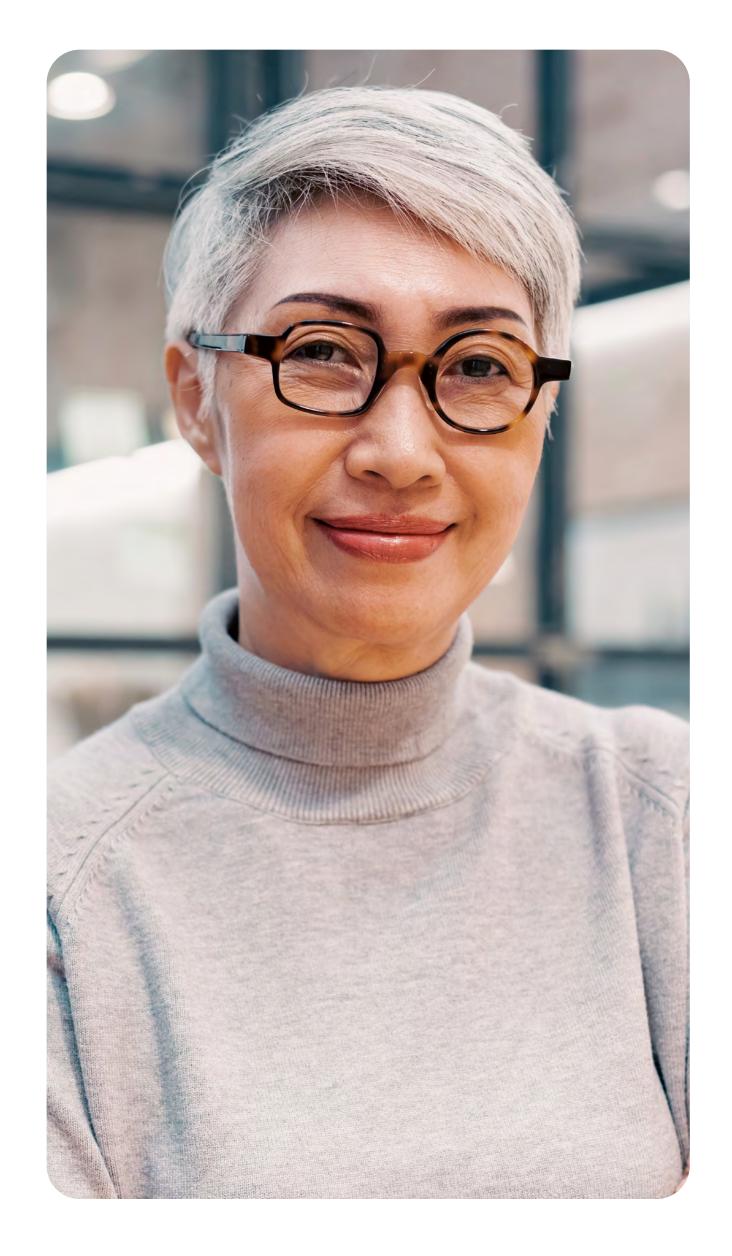
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Appendix 1: Detailed Quantitative Methods

Study Design, Setting and Data

We used linked health administrative datasets to conduct a repeated, cross-sectional analysis examining MHA-related physician visits and emergency department (ED) visits in Ontario over a 10-year study period from April 2012 to March 2022. The study period was segmented into 40 quarters of observation (first quarter of observation = April 1, 2012, to June 30; last quarter of observation = January 1, 2022, to March 31, 2022). All Ontario residents enrolled under the provincial health insurance plan receive universal, publicly funded access to medically necessary physician services and ED care.

The main sources of data used to create our study population and measures were the Ontario Registered Persons Database (RPDB), the Ontario Health Insurance Plan (OHIP) claims database, and the National Ambulatory Care Reporting System (NACRS). The RPDB provides basic demographic information (age, sex, date of birth, date of death for deceased individual) for those enrolled in the provincial health program; it also indicates the time periods for which an individual was eligible for publicly funded insurance benefits and the best-known postal code for each registrant on July 1st of each year. The OHIP claims database contains information on inpatient and outpatient services provided to Ontario residents eligible for the province's publicly funded health insurance system by fee-for-service health care practitioners (primarily physicians) and "shadow billings" for those paid through non-fee-for-service payment plans.

Each OHIP claim has a single diagnostic code attached, based on the physician's judgment, that describes the medical reason for the visit.

The NACRS is compiled by the Canadian Institute for Health Information (CIHI) and contains administrative, clinical (diagnoses and procedures), demographic, and administrative information for all patient visits made to hospital- and community-based ambulatory care centres (EDs, day surgery units, hemodialysis units, and cancer care clinics) in Ontario. Diagnoses in NACRS records are made by trained medical record abstractors using established coding practices and standards. These datasets were linked using encoded identifiers and analyzed at ICES.

The use of data in this project is authorized under section 45 of Ontario's Personal Health Information and Protection Act (PHIPA), which does not require review by a research ethics board.

Study Population and Measures

For each of the 40 quarters of observation, we used the RPDB to include all Ontario residents, between the ages of 0-105 years, who were alive and eligible to receive health care services in the province. Those who had no contact with the health care system in the 8 years prior to a quarter were excluded as such individuals likely represent individuals no longer residing in Ontario.





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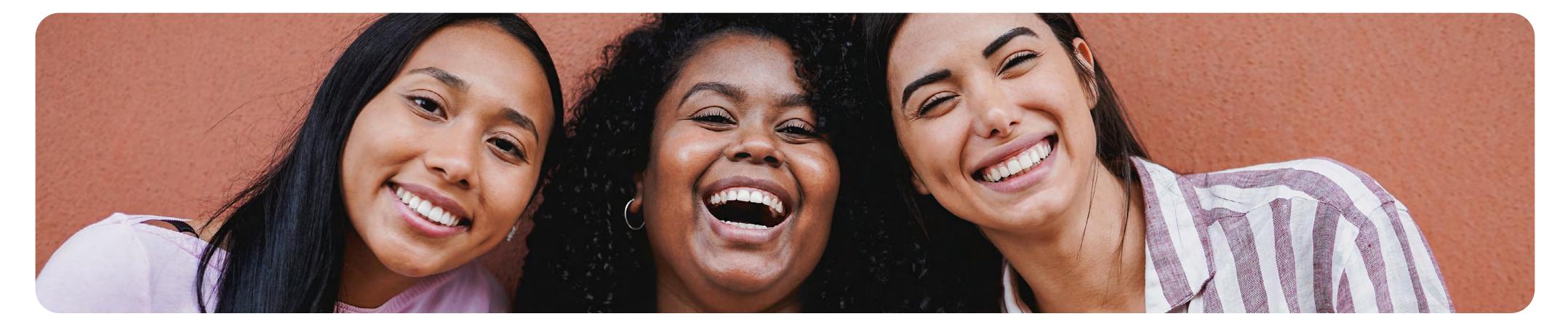
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For each Ontario resident in a study quarter, the best yearly postal code estimate from RPDB was used to establish their dissemination area (DA) of residence. We then linked Statistics Canada profiles at the DA-level, generated from 2016 Census data, to generate geographically based sociodemographic measures. These measures included neighbourhood income quintile (based on the income per single-person equivalent for each DA in the province), as well as quintile rankings for three dimensions of the Ontario Marginalization Index (Material resources, Households and dwellings, and Age and labour force). We excluded residents who did not have a valid Ontario postal code in the study quarter as linkage to geographic-based sociodemographic measures was not possible for these individuals. Last, we used the best yearly postal code to obtain the Ontario Health (OH) region of residence (North West, North East, West, Central, East, and Toronto), which are based on consolidated geographical boundaries previously used to define the Local Health Integration Networks.

Using previously established methodology, we measured the number of MHA-related physician visits and ED visits in Ontario for each study quarter. To determine MHA-related physician visits, we used the OHIP claims database to identify any office-, home-, long-term care, or virtual/phone-based visits to a: 1) psychiatrist, regardless of the diagnosis; 2) family physician/general practitioner, with an MHA-related diagnosis; 3) pediatrician, with an MHA-related diagnosis or specific service code denoting MHA care. We only counted one OHIP claim per person per day to a given physician as a visit to avoid potential overcounting. The NACRS database was used to identify any encounters with the ED where MHA was coded as the main problem/reason for the visit. ED visits representing transfers from a previous institution were excluded. Individuals could contribute multiple MHA-related physician visits and ED visits within a given study quarter. In addition to measuring all MHA-related physician and ED visits, we used relevant diagnostic codes to group MHA-related visits into the following categories: psychotic disorders, mood and anxiety disorders, substance use disorders, behavioral and developmental disorders, and other MHA disorders.

Statistical Analysis

We computed the number of MHA-related physician visits per 100 and the number of MHA-related ED visits per 1,000 for each study quarter. These visit rates over the 10-year study period (40 quarters) were plotted. For the latest quarter of observation in our study period (January to March 2022), we stratified MHA-related physician visit and ED visit rates by neighbourhood income quintile, material resources quintile, household and dwelling quintile, age and labour force quintile, and OH region of residence. To quantify differences in MHA-related physician and ED visits within each of the above sociodemographic characteristics, we used rate ratios (i.e., Rate_{group} 1/Rate_{group} 2) to compare the visit rate in the most marginalized quintile to the rate in the least marginalized quintile. Each analysis was conducted for all MHA-related visits, and separately for each diagnostic category (i.e., reasons for visiting).





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Appendix 2: Detailed Co-Analysis Methods

After reviewing the preliminary data, PAC members responded to the following prompts in small working groups (prompts are numbered and member responses to these are on coloured notes):

1. Are there key words or themes that come to mind when you look at these results? (for example, "surprising, "concering", "need more information", "unfair", etc.).

Figure 1a:

Not surprising - this (COVID-19 pandemic) was a catastrophic event with worldwide impact

Curious - what specific causes/issues in the pandemic caused the uptick in visits? How did they feel entering healthcare spaces early as infections soared w/o vaccines?

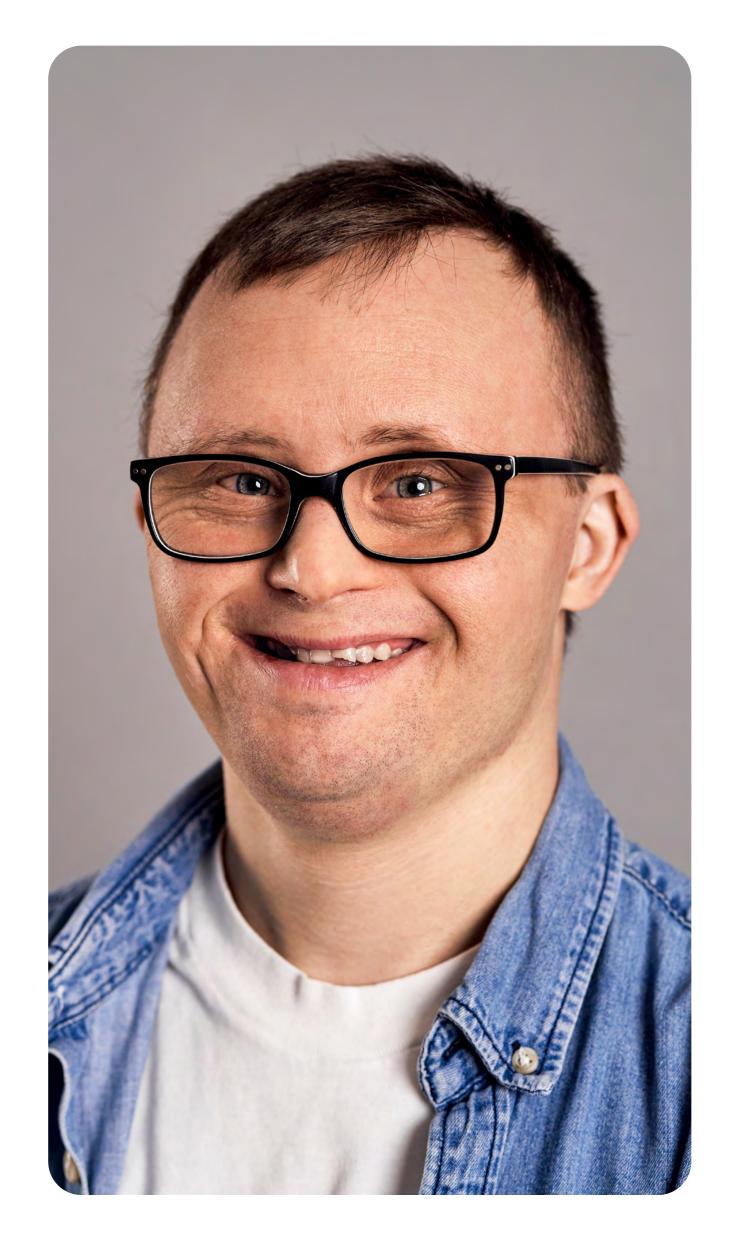
Troubling - calls to the need for better access to modd and anxiety-related support accessible through different mediums (i.e., not just through hospitals)

Figure 6:

Concerning - areas with the highest diversity having less MHA doctor visits may speak to the lack of access

Revealing - many communities experience violence in healthcare settings. They may not receive benefits from seeking mental health support in clinics/hospitals due to racism, etc.

Noteworthy - many may not know mental health services exist and mental health issues may not be openly discussed in some communities







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- 2. a) Summarizing your above key words themes, what do you think this data might mean or is showing? Is it different than what we discussed in the presentation?
 - b) Is there anything else you would like to know or clarify that is missing from the results?

Figure 1a:

I think it demonstrates the need for increased mental health support and services in Ontario post-pandemic

This data speaks to the reality we phase on the effects of the pandemic

- a) Demonstrates the harm of the pandemic on peoples mental wellbeing
- b) Would like to see the sociodemographic make up (especially geography) of those who make these visits

Figure 6:

Need for increased access to mental health services, advocacy, and accessibility of support across neighbourhoods

- a) Demonstrates the lack of benefit and inaccess of mental health services for the most marginalized communities
- b) Comparison to other clinical service usage (e.g. ED, GP visits)





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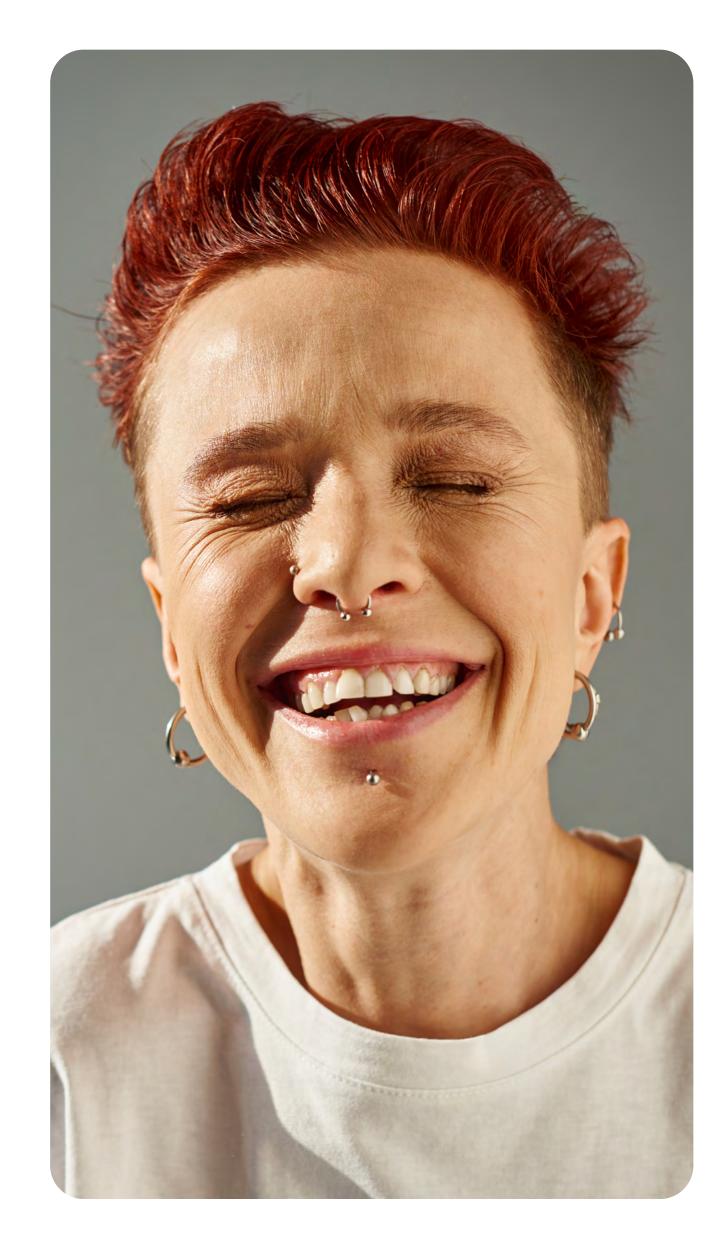
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Several specific comments from PAC members are also quoted below because they resulted in a pivotal reconstruction of the data analysis plan:

- "It would be interesting to contrast the emergency department visit patterns against these outpatient trends. Are people going to the emergency department for service due to a lack of access to outpatient services?"
- "The emergency department is a common route for folks who don't have a family doctor, so this may be relevant to consider if the question is about access to care. We (the PAC) believe that this should be counted. If you're experiencing homelessness, you usually don't have a doctor. Vast swaths of housed people don't have family doctors either. Are walk-in clinics being used as a substitute? Are emergency departments being used as a substitute?"
- "We want to look at hospital visits separately from outpatient visits. This would allow us to tease out whether folks turn to the emergency department as a default due to a lack of access to outpatient services. What is the quality of service like in these cases (e.g., continuity of care)?"
- "By looking only at outpatient services, we are also likely missing most/all extreme psychotic episodes (which often end up in the emergency department instead). We hope these folks will get outpatient follow-up care, but many do not. There is very little follow-through in the community. You have an episode in the hospital, you're discharged, and you'll be referred to your family doctor if you have one. However, few cases end up being followed up on" (per the PAC's experience in their communities).







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Appendix 3: PAC Recommendations for Communicating ON-MARG to a Public Audience

The Ontario Marginalization Index (ON-MARG) is a geographically (Census) based index developed to quantify the degree of marginalization occurring across the province of Ontario. It combines discrete, yet related, census variables into four broader dimensions that contribute to the process of marginalization: households and dwellings, material resources, age and labour force, and racialized and newcomer populations. See <u>Inventory of race and related data within the ICES repository</u> or the ICES <u>Data Dictionary</u> for a more detailed description of ON-Marg.

ICES is making new recommendations to enhance and contextualize use of the racialized and newcomer populations dimension (referred to as "ethnic concentration" prior to 2021). These recommendations come directly from members of ICES' <u>Public Advisory Council</u> (PAC) through their work with ON-Marg as part of a <u>PAC-led Applied Health Research Question</u>. Based on suggestions from the PAC, reviewing best practices in the use of race-related data, as well as ongoing consultations with Dr. Arjumand Siddiqi on race and social variable use at ICES, the following recommendations could be considered to optimize communication of the ON-Marg Index. Many of these recommendations are echoed in the <u>User Guide: 2021 Ontario Marginalization Index (publichealthontario.ca)</u>. We encourage scientists to continue using the ON-Marg Index, especially in the absence of individual-level race and social data.

1. Avoid stigmatizing language and data labels

The categorization of "most marginalized" to "least marginalized" quintiles in the context of racialized and newcomer populations was concerning for PAC members, as it risks portraying deficit-based interpretations. However, PAC members also recognized that it is important to highlight that racialized populations and newcomers experience racism, discrimination, and marginalization.

- Rather than categorizing quintiles from "most/least marginalized", consider more specific labels such as "neighbourhoods with most/least racialized and newcomer populations".
- Include all 5 quintiles of each measurement, regardless of the dimension.
- If using the term 'marginalized", frame it clearly as a situation actively imposed by social structures on these populations. Avoid describing populations as 'marginal" as a passive descriptor or trait without this context.





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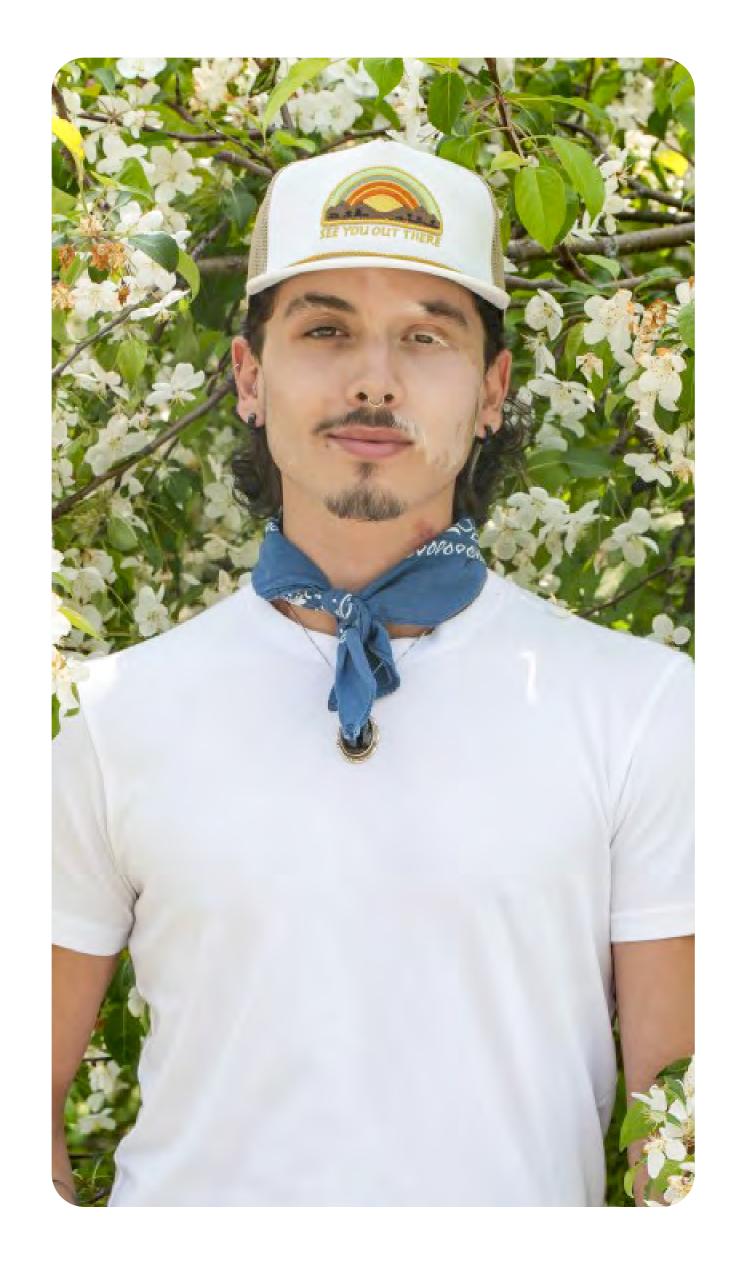
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2. Be transparent about the data source's limitations

ON-Marg assigns Factor Scores at a neighbourhood level. Some people within a neighbourhood are not going to be represented by the neighbourhood average.

- There's a risk of misclassifying individuals if ON-Marg is used as a proxy for individual status; risk is proportional to the size of geography used. Using DA-level poses lowest risk of misclassification if using ON-Marg as a proxy for individual-level data.
- Not everyone has the opportunity to respond to the Canadian Census.
- Temporary foreign agricultural workers and people living in congregate settings are not asked some of the census questions, so findings from ON-Marg may not be generalizable to these populations.

The racialized and newcomer populations dimension encompasses the experiences of multiple, distinct communities.

This dimension should <u>not</u> be used to summarize the experiences of one specific community in isolation or make inferences that could harm or stigmatize certain communities. For example, while Black populations are included in the indicators, combining all racialized groups together may obscure the experiences of this distinct racialized group (i.e., the impacts of Anti-Black racism). "Immigration" and "racialization" are also distinct concepts that should not be conflated.

 Scientists may wish to consider supplementing analyses with other approaches to better understand the impacts of specific driving factors causing health inequities, such as engagement with populations being studied to add qualitative lenses to support any research implications.

3. Contextualize explicitly

Contextualization can help to proactively prevent readers from making assumptions of causes related to biology or poor individual choices.

- Scientists should carefully consider why they are using the Index and how it can be used to name health inequities and/or racism explicitly.
- Consider including a 1-2 liner of contextualization to accompany all results/graphs that make clear that race and ethnicity are social constructs and that systemic racism directly impacts outcomes related to health and service use.

For more information, explore:

- Guidance from ICES on page 49-57 of the <u>Guidance</u>
 <u>Document & Framework for Anti-Racist Approaches</u>
 to Research and Analytics
- Frequently Asked Questions
- Public Health Ontario: Ontario Marginalization Index Updates and Products
- User Guide: 2021 Ontario Marginalization Index

















