

ICES Public Advisory Council

Annual Report: 2024/2025



Purpose of this Document

The purpose of this document is to summarize the activities pertaining to the ICES Public Advisory Council in 2024/2025. The summary includes information on:

- Overview of the PAC
- Recruitment of New Members
- PAC Meetings and Activities
- Member Feedback

ICES Public Advisory Council (PAC) Overview

Progress in Year 5

The ICES Public Advisory Council was formed in 2019 and is made up of members of the public from across Ontario. The council represents the public's voice and guides ICES on what matters most to Ontarians in terms of health data research and policy. Their thoughts, perspectives, and values inform ICES research activities and influence how ICES researchers use data to improve Ontario's health care. We are currently in our fourth iteration of the Council and Year 5 of its work.

The Public Advisory Council (PAC) is the primary mechanism for ICES to engage with the public at an institutional level. The PAC guides topics that the ICES Management feels require or would benefit from, from the perspective of the Ontario public. The PAC also provides feedback to ICES researchers and other areas of the organization that come to the group seeking guidance on matters related to the public.

The PAC continues to guide ICES on what matters most to Ontarians in terms of health data research. The thoughts, perspectives, and values of the PAC influence ICES' research and the way ICES researchers use data to improve and evaluate healthcare.

PAC Membership

As of March 31, 2025

The PAC includes individuals from across Ontario and aims to reflect the diversity of those whose data reside in the ICES Data Repository. Recruitment for new members to join the ICES PAC began in the 2023/2024 reporting period and was completed with the addition of seven new members chosen during this period.

The selection process for PAC membership has not changed from the previous year, and was as follows:

- Applicants submit an online application to express interest
- The ICES Public & Community Engagement, Knowledge Translation (PCEKT) Team reviews all applications and determines those chosen for a 30-minute phone screening
- Applicants attend phone screening based on availability and interest
- The PCEKT Team determines successful applicants and notifies those chosen for the PAC
- Those not chosen to join the council are encouraged to join the Public Engagement mailing list and apply again for future recruitment cycles
- Applicants who accept the PAC offer are sent a Terms of Reference and orientation package, and all new members attend a virtual PAC orientation session prior to joining the full PAC

There are a total of 15 PAC members, with the next round of recruitment scheduled for Spring 2025.

ICES staff who were present at the 2024 PAC meetings were as follows:

Laura Ferreira-Legere, Senior Manager, Public & Community Engagement, Knowledge Translation Sabella Yussuf-Homenauth, Senior Officer, Public & Community Engagement, Knowledge Translation Elise Leong-Sit, Senior Officer, Public & Community Engagement, Knowledge Translation Michael Schull, Chief Executive Officer
Astrid Guttmann, Chief Science Officer
Pierre Leclerc, ICES Board Liaison
Other ICES staff attend periodically as needed for updates.

PAC Chair

A new position of PAC Chair was created in March 2024 with the goal of having an existing member trial this position. The aim of having an existing PAC member serve as Chair is to provide peer leadership and perspective for the group, and work with ICES staff to guide the PAC in its key responsibilities/roles.

Simisola Johnson has served as the PAC Chair for the past fiscal year and has expressed a desire to extend her term as PAC Chair. In discussion with Simisola, it was determined she would continue in this role for an additional and final year. In March 2026, the position will reopen to existing members who have been on the PAC for at least 1 year and would like to self-nominate.

Summary of Activities

April 2024 – March 2025

PAC Meetings

The PAC has met four times over the past year, with an additional optional meeting occurring in January. Three of the four meetings, along with the optional meeting, occurred virtually. The PAC's annual hybrid meeting was held on October 30, with 8 members attending in person, 4 members participating online, and 3 members unable to attend. The hybrid meeting incorporated feedback from the previous year to provide more opportunities for networking and fewer agenda items. In addition, a dedicated working group was established to help plan the hybrid meeting and provide insight into what content should be reviewed and discussed at the meeting. The meeting was once again held at the Novotel Toronto Centre from 2:00 p.m. to 7:00 p.m. EST.

A PhD Senior Policy Advisor in the Digital & Analytics Strategy Division of the Ministry of Health & Ministry of Long-Term Care hosted the optional meeting held in January 2025. The meeting sought to test materials designed for a large provincial consultation with the public and health partners on Ontario's Civic Engagement Strategy Advisory Report. Ontario's Civic Engagement Strategy outlines a plan to explore the best ways to engage Ontarians in understanding how their health data is collected, used, and shared. Through consultations, the ministry will gather feedback on how to implement the Report's recommendations effectively. In advance of conducting these consultations, the ministry is testing consultation materials with expert advisory groups, such as the PAC, to ensure they are clear, engaging, and accessible for the public. The meeting was well-attended by nine PAC members.

PAC Applied Health Research Question (AHRQ) Publication

In February 2022, PAC members collectively developed a research question to be answered by the ICES AHRQ program. This process involved brainstorming and prioritizing topic areas. The PAC collectively selected a research topic area and created a research question that could be answered using ICES data and analytics. This integrated knowledge translation approach enabled the ICES PAC to participate in the research process, utilizing ICES data and leading the knowledge translation activities.

In January 2025, the project was formally completed, and a comprehensive report, a results video codeveloped by a smaller PAC working group, and a tailored resource for other groups interested in similar work were launched. The full publicly available report, corresponding resources on public-led research, and results video are all available here: ICES | Mental health-related visits to doctors and emergency departments in Ontario: a public-led exploration and analysis

The PAC AHRQ report results were also reported by the media and published in Sudbury News. Northerners are isolated by different mental health services - Sudbury News

Since the publication of our report and resources, two PAC members also spoke about this project and public engagement more broadly on our ICES In Our VoICES Podcast: Public and Patient Research | ICES

PAC's Advisory Feedback

This year, the PAC contributed to several organizational initiatives, a scientist-led project, and provided feedback on our own PAC-related processes and procedures as a group. A PhD trainee presented their project for feedback on how to describe 'avoidable' emergency department usage, understand factors of 'avoidable' emergency department visits, and explore the impact of frequent, 'avoidable visits on patient outcomes. Approximately 8 months after this project was brought to the PAC, we received qualitative feedback from the PhD trainee on the experience presenting to the PAC:

"The ICES PAC meeting informed my work in several key ways. The focus of my work has shifted entirely from onus on the patient to onus on correctly designing a system to avoid patients having to make difficult decisions regarding their care. Meeting with the PAC was such a valuable experience in informing me how I handle my work going forward."

Additionally, the PAC provided feedback on the ICES Communications department's plan for a broader reach to public audiences. The Communications team presented at two PAC meetings to gather thoughts, feedback, and suggestions related to their strategy. In addition, the ICES Data and Analytic Services (DAS) department also presented to the PAC on private sector research, opening the floor to the PAC's comments, questions and concerns related to this work. Finally, much of the PAC's feedback this year was also related to the group's process and procedures, as well as how we can better identify priorities for the PAC in the coming months and years. Much of this feedback also centred on the need for a better understanding of the PAC's broader impacts, which we will also explore in the upcoming fiscal year.

PAC Quality Improvements

This year, with assistance and guidance from the PAC Chair and member feedback, two significant quality improvements were made: 1) In the 5th official year of the ICES PAC, we realized the extensive amount of orientation that is required for new members to understand better the work of ICES, our data, and how our organization sits in the broader context of the Ontario health and research space. We also realized there were gaps in our orientation material that prevented members from fully understanding some of the bigger picture. We revised our orientation materials for new members, including the content's formatting. We tailored the content better to describe the role of the PAC within ICES, how ICES differs from the government, and the role of PAC members. We also formatted the content into a video and written package ahead of our formal orientation meeting, providing participants with different options for reviewing the material. 2) In addition, prior to this fiscal year, we had a maximum 3-year term for each member. Still, we realized that it typically takes the first 1 to 2 years of a member's term to feel comfortable with the materials, and we tend to have the most fulsome discussions later in a member's term. To address this gap, we now offer members the option to extend their term for a maximum of 6 years. At the end of this fiscal year, half of the outgoing members decided to continue for a second term.

Members' Evaluation

Annual Evaluation

PAC Annual Evaluation

All PAC members are invited to complete an annual evaluation survey for every year of their term. The goal of the evaluation is to try to address the comments and make improvements to the way the PAC is run the following year. The survey was anonymous and was based on the Public and Patient Engagement Evaluation Tool (PPEET) Version 2.0 (licensed under a Creative Commons Attribution-Non-Commercial) by McMaster University.

The March 2025 annual evaluation was completed by 11 PAC members, representing the highest participation rate in three years. Members generally provided positive feedback on communication and overall work, with these areas also showing year-over-year improvement. There were also areas for continued improvement flagged by members, with open-ended comments that helped describe the changes they wanted to see. The areas often related to sharing views/perspectives and the impact/influence of the PAC:

- Opportunity to 'debrief' after our meetings
- New mechanisms to allow different ways to participate and ensure equal participation
- More public awareness of ICES and ways to integrate our work
- Ways to measure our impact in the organization

An area we focused on improving last year was the understanding of PAC members regarding the overall purpose of the PAC and its role within the organization. To help improve this area, we enhanced our orientation materials (as mentioned above) and also provided more background information on topics such as our data and organization in various meetings throughout the year. We observed a year-over-year improvement in this area, with all survey respondents indicating that they strongly agreed or agreed with the statements regarding understanding the purpose and having the necessary resources to carry out their role.

Members this year generally felt that they understood the group's goal and its place within the organization. Still, they sought a deeper understanding of the impacts of some of their work, including follow-up on individual projects to see how feedback was utilized. Members also felt they were able to express their views freely, but with a need for some improvement to ensure everyone has an opportunity to reflect and share. All members agreed that the meetings themselves are well-organized, clear, and they feel supported by the ICES Staff.

The feedback from both the annual and end-of-term evaluations will be used to improve activities for the coming year. A snapshot of results from the survey is included below:









