



ICES Public Advisory Council Annual Report: 2022/2023



Purpose of this Document

The purpose of this document is to provide a summary of the activities pertaining to the ICES Public Advisory Council in 2022/2023. The summary includes information on:

- Overview of PAC: Goals and Progress
- Membership and Recruitment
- PAC Meetings and Activities
- Member Feedback

ICES Public Advisory Council (PAC) Overview

Progress in Year 4

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 for health data research. 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 third iteration of the Council and Year 4 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 provides guidance on topics that the ICES Management feel require, or would benefit, from the perspective of the Ontario public. The PAC also provide feedback to ICES researchers and other areas of the organization that come to the group seeking guidance on matters pertaining to the public.

In 2022, the last cohort of originally PAC members established in 2019 completed their term, and 9 new members began their 3-year term. The PAC continues to guide ICES on what matters most to Ontarians for health data research. The thoughts, perspectives and values of the PAC influence ICES' research and the way data is used by ICES researchers to improve and evaluate health care.

PAC Membership

As of March 31, 2023

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 May 2022. Anyone residing in Ontario was invited to apply for the PAC and online applications were reviewed based on an understanding of the commitment, availability, and interest. As of 2021, ICES adopted a staggered membership approach to maintain continuity of the PAC where new members are added every 18 months. No educational background or training in research, science, healthcare, or data was required to be a member of the PAC.

During the recruitment process, particular care was taken to capture perspectives of the public across geography, age, ability, cultural diversity, education, membership to the 2SLGBTQI+ community, and experience with the health care system to the best of our ability. ICES will continue to strive to capture diversity within the PAC as it evolves over time.

Selection process for PAC membership was as follows:

- Applicants submit online application to express interest
- The ICES Public Engagement and Knowledge Translation (PEKT) Office reviews all applications and determines those chosen for a 30-minute phone screening
- Applicants attend phone screening based on availability and interest
- The PEKT office 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 and sent a Terms of Reference Document and Orientation package
- All new members attend a virtual PAC orientation session prior to joining the full PAC

The recruitment for new members occurred over several months, with over 50 applicants and 22 interviews conducted. Ultimately, 9 individuals from across Ontario were chosen to be new members. There are now a total of 20 PAC members, with the next round of recruitment to occur in Spring 2024.

ICES staff that were present at 2022 PAC meetings were as follows:

Laura Ferreira-Legere, Senior Manager, Public Engagement and Knowledge Translation

Sabella Yussuf-Homenauth, Public Engagement and Knowledge Translation Officer

Elise Leong-Sit, Public Engagement and Knowledge Translation Officer

Michael Schull, Chief Executive Officer

Astrid Guttman, Chief Science Officer (On Sabbatical until October 2023)

Michael Paterson, Core ICES Scientist, Interim Chief Science Officer

Geoffrey Rowan/Donna Kline, ICES Board Liaison with the Public Advisory Committee

Other ICES Staff attend periodically as needed for updates.

Summary of Activities

2022 – 2023

PAC Meetings

The PAC has met five times over the past year, with most meetings held online due to the ongoing COVID-19 pandemic. The PAC had their first hybrid meeting on October 26, 2022. Prior to the meeting, attendance intention was 50% in-person and 50% online. Due to illness and unexpected conflicts for some members, 6 PAC members attended in-person, 10 members attended virtually, and 4 members could not attend.

The PAC has provided input on several initiatives, including the ICES strategic plan refresh, the PAC AHRQ question, the ICES revised website, and overall reflection and feedback on the PAC activities since inception. Four members of the PAC also participated in a virtual workshop on knowledge mobilization at the ICES research forum. One PAC members also participated as a speaker in a plenary session focused on: The Promise of Cross-Sectoral Data for Addressing Health Equity.

PAC Applied Health Research Question (AHRQ)

In February 2022, PAC members collectively developed a research question to be answered by the ICES AHRQ program. This process involved brainstorming and prioritizing steps (facilitated by ICES) in which the PAC collectively selected a research topic area (Changes in Mental Health and Addictions Service Use Over Time) and created a research question that could be answered using ICES data and analytics. The chosen research question was "What was the most frequent cause for outpatient mental health visits (over time)?" and was approved by the AHRQ team for analysis.

The PAC had anecdotal knowledge on the state of mental health care in Ontario but were curious about how frequent outpatient visits were for different mental health conditions and across different groups of people (e.g., diverse race and ethnicities, lower income, etc.). Both the PAC and Mental Health and Addictions (MHA) Team at ICES acknowledged that the reasons for outpatient mental health visits and trends over time are not frequently reported and would be worthwhile to explore. The first round of analysis was shared with the PAC in October 2022 and members were given the opportunity to provide feedback and share their thoughts on interpretation of the data. Based on feedback from the PAC, emergency department visits were added to the analysis and the final round of results were shared with the PAC in February 2023. The PAC voted on which results were most important to either a) include in a report, b) include in a tailored knowledge product for the public, or c) include in both. The results of the vote will inform the products developed by the PAC Working Group and ICES staff over the next year.

PAC Working Group

A smaller PAC working group was assembled to meet more frequently and help determine what kinds of plain language products would be created and disseminated on the PAC AHRQ results. With the launch of the PAC AHRQ, there was a need for more comprehensive, public-friendly materials that can share the methods and results to a broader audience than an academic paper alone. The working group also helps to develop other products as needed. For example, the working group's first meeting in January 2023 focused on developing a presentation template for scientists and project teams presenting to the PAC. The working group prioritized areas that must be included in each presentation, depending on topic, and the template was finalized in March 2023 for pilot use.

Members' Evaluation

End-of-term and Annual Evaluations

PAC End-of-term Evaluation

This year, 4 of the 10 outgoing members voluntarily provided their thoughts and feedback on their participation on the PAC during their 3-year term. 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.

Overall, the feedback was positive with all respondents indicating that they enjoyed their time on the ICES PAC and felt their contributions made a difference to the organization. Some respondents mentioned that prior to their involvement on the PAC, they weren't aware of ICES, but now felt confident in their ability to understand the organization's work, mission, and goals.

Almost all respondents mentioned that they wish they had more in-person meetings or opportunities to connect, which unfortunately did not happen due to the COVID-19 pandemic. Many wanted to feel more connected to each other as PAC members. Some also felt that they wanted more tangible ways to see their work influencing ICES. They felt at times it was hard to tell which areas could be influenced versus controlled by policy. There was also a desire for new ways to share feedback that would allow all voices to be heard equally, as with a 20-person council, not all feel comfortable sharing during the meetings.

PAC Annual Evaluation

All PAC members are invited to complete an annual evaluation survey for the remainder of their term. This practice was implemented in March 2023, and therefore the results are considered a baseline assessment. 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 2023 annual evaluation was completed by 6 PAC members. In terms of communication and support from ICES, all respondents indicated they agreed or strongly agreed that they had adequate information and support in their role. In terms of sharing views and perspectives, most agreed that they could do so freely, while some mentioned they felt it more challenging due to outspoken members. Members appreciated the welcoming and open environment to share and express opinions but mentioned more time and/or more frequent meetings might be needed. There was also a comment to continue to work towards using simplified language over acronyms which can be confusing.

Most members felt that the PAC had impact and influence across the organization, although similar to the comments above, many felt that the group needed more time and/or more frequent meetings. All members agreed or strongly agreed that they were more informed about health research and ICES because of their role and that they are overall satisfied with being member a member of the PAC.