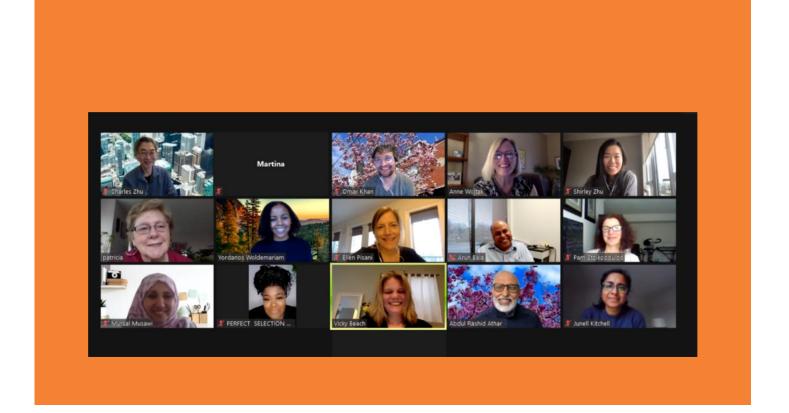


COMMUNITY ADVISORY COUNCIL 2021/22 ANNUAL REPORT





From the Chair

When asked to write a few introductory remarks reflecting on the past 12 months of working with our Community Advisory Council, it was no easy feat – there was lots to reflect on. 2021 marked the first full year of us living with and managing through the ever-evolving COVID-19 pandemic, which has felt like a sprint and a marathon. The physical, emotional and mental impacts of the pandemic, both on an individual level and as a collective, have been indisputable. However, in joining the Community Advisory Council this past year, it helped me recognize I was not alone in my frustrations and aspirations for what health and social services in East Toronto could be.

The Community Advisory Council has served as an important voice and collective of patients, clients, family members, unpaid caregivers and community members that represent the diverse population of East Toronto. Together, we brought our lived experiences to shape and inform how East Toronto Health Partners designed, delivered, and helped individuals access health and social services in East Toronto. This past year has been tremendously difficult for each and every one of us for different reasons, so I would like to extend my deepest thanks and gratitude to the 16 Community Advisory Council members for their continued commitment and advocacy, both locally and systemically. Community Advisory Council members have been actively involved in a number of initiatives, working groups and presentations, including East Toronto Health Partners' vaccination strategy and co-designing the Caregiver NICE Fund. These collective efforts have resulted in improved experience and access to care and services for communities served by East Toronto Health Partners. Furthermore, these accomplishments been foundational to shaping the Community Advisory Council's path forward for the next year, and beyond.

I would also like to extend my thanks to the leaders across East Toronto Health Partners for their continued commitment in including the Community Advisory Council in key operational and strategic conversations and initiatives. Recognizing the importance and value of patient, client, family member, unpaid caregiver and community member voices is critical to designing and delivering health and social services that meet the needs of East Toronto's diverse population, today and tomorrow. I am looking forward to our continued partnership with the leaders across East Toronto Health Partners and embracing a culture of co-design.

As someone who has always preferred to take a glass half-full perspective, I am excited for the road ahead. On a more personal level, I am excited to continue bringing my lived experiences as a second-generation Chinese-Canadian who has called East Toronto home her entire life (fun fact: I was born at Michael Garron Hospital) and have been able to see and experience the community grow, evolve and change



first-hand. My experiences, and the experiences of my non-English-speaking, aging relatives and family members, motivates me to continue advocating for patient-centred culturally sensitive care and supports for unpaid caregivers and family members. Just like how I bring my unique personal experiences to the Community Advisory Council, so can you. Improving health and social services locally and systemically is a marathon, and it cannot be done without the diverse voices and perspectives of patients, clients, family members, unpaid caregivers and community members. If you are interested in sharing your experiences and are passionate about being involved in change, please consider joining our Community Advisory Council!

Shirley Zhu
Co-chair, Community Advisory Council



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Summary

East Toronto Health Partners' (ETHP) Community Advisory Council (CAC) is pleased to present the 2021/22 Annual Report. The report summarizes the CAC's activities for the period of April 2021 to March 2022 – an inaugural year during which ETHP's interim Patient and Family Advisory Council (PFAC) grew its membership and expanded its involvement in ETHP's operations.

The expanded CAC includes patients, caregivers, family and community members with diverse backgrounds and experiences. The new members are East Toronto residents and community leaders who have expressed interest in improving the local healthcare system and making a difference in their neighbourhoods.

The CAC mandate is to engage the community within East Toronto to ensure ETHP places patients and their caregivers at the centre of delivering integrated healthcare and social services.

During this first year of the expended CAC, the work of the council focused on some foundational pieces such as developing the terms of reference, the patient and caregiver advisors (PCAs) recognition framework, the ETHP engagement strategy as well as increased involvement of CAC members in various ETHP initiatives.

The work wouldn't be possible without the dedication of our committed members who collectively contribute numerous volunteer hours of their time to the CAC, attending a multitude of meetings, bringing to the table the patient and caregiver voice.

The CAC is grateful for the support of ETHP's leadership and recognize this as a key element of our success.



Bringing the Patient and Caregiver Perspective to ETHP

About the Community Advisory Council

At the beginning of 2021, as part of an ongoing commitment to work more collaboratively with patient and caregiver advisors, ETHP decided to expand its interim Patient and Family Advisory Council (PFAC), a small group of five advisors that was brought together in August 2019, shortly after ETHP was declared one of Ontario's first Ontario Health Teams (OHTs). The recruitment of additional advisors was motivated by the desire to help ensure the voices of those who access and receive care in East Toronto continue to be reflected in ETHP's work. Ten new members joined the group and adopted the name Community Advisory Council (CAC).

The CAC meets once a month over the whole year, on a volunteer basis. The primary role of the CAC members is to share their experiences as patients, family members/caregivers and community members and provide feedback on different health-related programs and services to help improve care for people in East Toronto. Due to the COVID-19 pandemic, during the period of April 2021 to March 2022, all of the CAC meetings were online.

In addition to the 15 volunteer patient, caregiver, family and community advisors, the CAC meetings are attended by senior ETHP leaders: Anne Wojtak, ETHP lead, and Melissa Morey-Hollis, Vice President of Clinical Programs, Unity Health, as well as Lucy Lau, ETHP Communications Lead, and Nena Pendevska, ETHP Engagement Project Manager. The CAC is co-chaired by CAC members, Charles Zhu and Shirley Zhu, and Melissa Morey-Hollis. This model of joint leadership further underlines the importance of the partnership between ETHP and its patient and caregiver advisors. It reaffirms ETHP's recognition of the CAC as an important part of the ETHP organizational structure.

ETHP's commitment to the inclusion of patient and caregiver advisors' views and recommendation in significant decisions is also demonstrated by the inclusion of CAC representatives in ETHP's leadership structures. Two of the CAC members (one co-chair and one unpaid caregiver), are members of key decision-making bodies: the Leadership Group and the Operations Team. In addition, over the past year, CAC members have joined several other ETHP committees and working groups such as the Caregiver Advisory Group, the Primary and Community Care Response Teams, and the Asset Mapping and Navigation Steering Committee. Our goal for the future is to ensure CAC representation on all key ETHP decision-making bodies.



ETHP Community Advisory Council Members

Patient, Caregiver, Family and Community Advisors

Abdul Rashid Athar Junell Kitchell Jill Robinson

Arun Bala Patricia Maurice Pamela Stoikopoulos

Vicky Beach Desalegn Merga Martina W.

Kamika Hutchinson Mursal Musawi Charles Zhu (Co-Chair)

Omar Khan Ellen Pisani Shirley Zhu (Co-Chair)

East Toronto Health Partners Staff

Anne Wojtak, ETHP Lead

Melissa Morey-Hollis, Vice President of Clinical Programs, Unity Health

Lucy Lau, ETHP Senior Communications Specialist

Nena Pendevska, Project Manager, OHT Initiatives, Engagement



Our Year in Review

Recruitment and Orientation



Members of ETHP's expanded CAC were selected following a four-month recruitment process, from January to April 2021, which helped ensure diverse representation of patients, family members/caregivers and community members in East Toronto.

This recruitment process involved consulting ETHP's interim PFAC and local community and grassroots agencies that are involved in community outreach work. This allowed these groups to co-design strategies with ETHP that helped engage populations of all ages and cultural and socioeconomic backgrounds. In addition, this engagement helped ensure the application and interview process were as low-barrier as possible.

Outreach strategies included developing flyers in

languages that are commonly spoken in East Toronto communities, such as Bengali, Farsi, Greek, Gujarati, Spanish and Urdu, and conducting virtual information sessions during the application stage to ensure those who were interested in applying to be a part of the CAC had the opportunity to ask questions and learn more about the role.

ETHP continues to accept applications from patient, caregiver, family and community advisors to support the creation of a broader network of advisors who can be matched to various ETHP initiatives based on their interests and experience. This is in line with the CAC's objective of increased engagement of patients and caregivers across ETHP. This group of volunteers will be invited to participate in future opportunities such as steering committees, working groups, workshops, surveys and focus groups.

To support the meaningful engagement of patient and caregiver advisors, the CAC revised its Terms of Reference; developed the role and responsibilities of members, cochairs and leadership group liaisons; and introduced the Code of Conduct for patient and caregiver advisors.



Hiring of the ETHP Engagement Project Manager

As part of an ongoing effort to increase the participation of community members in shared-decision making, CAC members joined the hiring panel for the Engagement Project Manager. Two of the CAC members worked together with two ETHP staff members to develop the role description, review job applications from qualified candidates, and interview those who were selected. The CAC members, as equal partners in the process, represented the interests of the CAC in the hiring of the Engagement Project Manager.

Recognition Framework

After extensive literature review and consultations with other organizations and OHTs, in July 2021, ETHP adopted the recognition framework for the engagement of patient and caregiver advisors. The framework outlines the criteria and amounts of the honorariums offered to the volunteer patient and caregiver advisors, and for the reimbursement of expenses (e.g. parking, travel, childcare, respite care). The small honorariums that are offered are in recognition of the many hours that volunteer advisors contribute while working alongside paid staff. With the framework in place, we also hope to remove some of the barriers for participation and increase the engagement of underrepresented groups.

Engagement Strategy



The ETHP engagement strategy was developed through a collaborative approach with members of the CAC, via the establishment of a joint working group, supported by ETHP's Engagement Project Manager. Ten CAC members were involved in the development of the strategy. The working group met weekly during the later parts of July and all of August to work on the different elements of the strategy. Input from

key ETHP staff was collected as needed, as well as from the Leadership Group.

The strategy builds on the ETHP Engagement Framework developed in 2019 and previous work completed in the area of engagement and aims to assist ETHP to plan and undertake effective community engagement. It includes specific recommendations on how to best involve community members as partners in the planning and design of an integrated care model for ETHP.



The goal of the strategy is to ensure that patients, caregivers, family, and community members are provided with meaningful and accessible opportunities for engagement that leverage existing strengths and assets within the community.

Furthermore, the strategy outlines a consistent approach to community engagement, by guiding when and how to undertake engagement activities, what approaches should be considered, and what are the various factors that facilitate engagement.

Patient Declaration of Values



The CAC began its work on the development of a Patient Declaration of Values (PDV) at the end of June 2021 by the creation of a small working group of CAC members. The CAC's proposed PDV was finalized in August with the intention to be shared for input with the PFACs of ETHP member organizations.

However, following a round of consultations with OHTs across the province, Ontario Health changed its approach in favour of adoption of the provincial Patient, Family and Caregiver Declaration of Values (PFCDV) developed by the Minister's PFAC. The adoption of the PFCDV as a common set of values across all OHTs will set a provincial standard for what patients, families and caregivers can expect from the healthcare system.

The CAC reviewed and endorsed the provincial PFCDV recognizing that the values in the declaration are universal in the context of people – centered, high-quality care. On the recommendation of the CAC, ETHP signed the required Ministry attestation while acknowledging that the PFCDV represents the minimum standard for what East Toronto residents should expect regarding care delivery by ETHP partners.

The adoption of the provincial PFCDV by all OHTs and their partners is a requirement of their Transfer Payment Agreements (TPAs). Therefore, in the coming year, the CAC will be working locally with partners and their patient and caregiver advisors to support the adoption of the PFCDV.

Survey to ETHP Partners

In an effort to increase collaboration with PFACs of ETHP member organizations, and to support the work related to the implementation of the PDV across ETHP, in January 2022 the CAC distributed a survey to all ETHP partners. The purpose of the survey was two-



fold – to learn more about how ETHP partners engage patients and caregivers in their work and to identify how many of the partners may already have their own PDVs in place. The survey received responses from 22 organizations and helped identify partners who were interested in collaborating with the CAC in the future. The CAC hopes to use the survey results to reach out to the other PFACs and establish a wider network of patient and caregiver advisors.

North American Conference on Integrated Care (NACIC) 2021 Presentation



In October 2021, CAC members had an opportunity to share the story of the development of ETHP at the NACIC, through the lens of the patients and caregivers who were involved in the work. The first NACIC was run as a virtual conference in partnership with the

University of Toronto, KPMG Canada, HSPN and iCOACH. Meaningful partnerships with patients, families and communities as one of the themes of the conferences generated significant interest among the OHTs and their PFACs. Three CAC members, Shirley Zhu, Charles Zhu and Jill Robinson, shared their perspectives on how patient and caregiver advisors contributed to key ETHP milestones; some of the lessons learned; and the plans to broaden engagement of patients, caregivers and our community.

RISE Co-design Workshop

Organized by the Rapid-Improvement Support and Exchange (RISE), the Partnering with Patients/Families/Caregivers in Population-Health Management Workshop in August 2021 was an opportunity for the CAC's co-chair Charles Zhu to share his experience of working as a community ambassador and a community leader of an East Toronto parenting group. The purpose of the workshop was to invite PFAC members of OHTs who were involved in co-design to share practical examples and lessons learned from the process. ETHP was one of two OHTs that were invited to participate in this workshop, part of a series of learning sessions on population-health management. A recording of the workshop is available online.



ETHP Vaccination Strategy



Since December 2020, ETHP has engaged partners, community members, and grassroots organizations to develop a COVID-19 Immunization Plan for East Toronto that is rooted in data, health equity and quality improvement. Throughout the vaccine rollout, ETHP's vaccine team encouraged feedback from partners, including clients, caregivers, families, and community ambassadors, to help ensure COVID-19 vaccines are as low-barrier as possible for local residents. CAC members

had an opportunity to provide feedback which included suggesting dates, times, and locations for pop-up vaccine clinics, and sharing the need for multilingual education materials that address community concerns.

ETHP Governance and Operating Model

In October 2021, the CAC and other internal and external stakeholders were engaged in a review and assessment of ETHP's governance and operating model. CAC members took part in a focus group to identify opportunities for improvement, which can be addressed through a new governance and operating model, to enable evolution to ETHP's next stage of maturity.

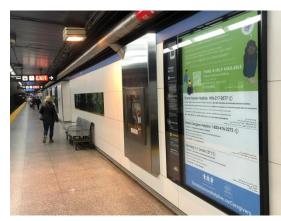
Evaluation Framework and Impact and Outcomes Workshop

The purpose of the developmental evaluation taking place at ETHP is to accelerate the development of all OHTs by learning from a select number of the first round of approved OHTs. For this reason, the Ministry of Health partnered with the Health Systems Performance Network (HSPN) to evaluate the development of these first OHTs. Patient and caregiver engagement is one of the areas that ETHP has chosen to evaluate by participating in the research study.

As part of this work, the CAC collaborated with ETHP's Evaluation Lead on the development of an evaluation framework for the CAC. In addition to the observational portion of the study, the CAC was involved in the development of the CAC logic model. CAC members took part in a workshop to identify the long-term impact and mid- and short-term outcomes of the CAC work. The work on the logic model was then used to inform the development of the CAC work plan for 2022/23. Results from the evaluation will be used by the CACs to further its development.



Co-design of the Caregiver NICE Fund and Caregiver Support Initiative



Many of the CAC members are also members of other ETHP committees and working groups that align with their experience and interests. In the past year, three CAC members, who are unpaid caregivers, were involved in the work of the Caregiver Advisory Group (CAG) and the co-design of two caregiver initiatives, the Caregiver NICE Fund and the Caregiver Support Initiative (CSI).

The Caregiver NICE Fund provides small amounts of funding for basic necessities or

other supports where no other funding sources are available or have been exhausted. The funding can either be for something that directly supports the caregiver or can be something that supports the person they provide care for – the intention is to provide whatever can help decrease caregiver stress and burnout. Funds are meant to be easier and quicker to access in comparison to other supports.

The Caregiver Support Initiative focuses on increasing caregivers' awareness of services available during surge, with specific focus on reaching those from ethno-cultural and diverse communities. Caregivers often lack information about the support services available. Caregivers from ethno-cultural and diverse communities, in particular, experience barriers in accessing and navigating existing services due to lack of linguistically and culturally appropriate sources of information, limited personal and professional networks in Canada, as well as financial, attitudinal and cultural barriers related to their sociodemographic status.

The process involved the caregivers in every step of the way, from the identification of the need for both projects, through the development of the funding proposals and codesign of both programs, to implementation and evaluation of the initiatives.

During this second year of implementing the NICE fund, caregivers not only helped review and streamline the application process, making it as low barrier as possible, but were also involved in the review and approval of the NICE fund applications.

The co-design process of the new caregiver support initiative involved several co-design sessions with the Caregiver Advisory Group to: a) identify the common barriers and challenges in finding and accessing information, b) identify solutions and resources (e.g. 211, Toronto Seniors Helpline, OCO, Connex Ontario, Telehealth ON), and c) identify the languages in the community (resources were translated into six different languages) and prioritize the dissemination channels. The caregivers were also able to



provide input to various documents, promotional materials, as well as review the translations of the resources and the caregiver website.

Presentations

Minister's Patient and Family Advisory Council (MPFAC) and the Ministry of Health's Patient Engagement Secretariat Presented by: Betty-Lou Kristy, Chair of the MPFAC

In February 2022, the CAC invited Betty-Lou Kristy and members of the Ministry of Health's Patient Engagement Secretariat to present the priorities for client and caregiver work and engagement at a provincial level. Members of the CAC were also interested to learn:

- a) how the MPFAC plans to work with OHTs and their respective PFACs to align on areas of shared interest; and
- b) how the MPFAC could support greater caregiver/client engagement through education or other resources for OHTs and identifying and sharing best practices in engagement.

The presentation was very informative and provided context and perspective for the work of the CAC.

Ontario Caregiver Organization (OCO)

Presented by: Bianca Feitelberg, Project Lead, Partnerships & Innovation and Alison Kilbourn, Project Lead, Strategic Partnerships and Innovation

This presentation provided an opportunity for CAC members to learn more about OCO's mandate and current activities, as well as the Caregiver ID initiative.

Algoma OHT – Caregiver ID

Presented by: Laura Tenhagen, Transformation Consultant at Algoma OHT

In follow up to OCO's presentation, CAC members expressed interest to learn more about the experience of OHTs in implementing the Caregiver ID initiative. For that purpose, we invited Algoma OHT to meet with CAC members and share their experience in implementing the Caregiver ID project and some of the lessons learned.

East Toronto Family Practice Network (EasT-FPN)
Presented by: Dr. Catherine Yu, Chair, Family Physician and Board Member at EasT-FPN

ETHP is one of the few OHTs that has a formalized network of family physicians working in East Toronto. The CAC invited Dr. Yu to share an overview of EasT-FPN, including



progress on the development of the physician network to date, as well as some of the significant challenges for access to primary care during the pandemic. Many of the CAC members in the past year expressed interest in better understanding the current state of primary care in East Toronto. In our discussions, members identified a number of emerging issues in accessing primary care. The presentation was an opportunity for members to share what they have been hearing from their community networks. In follow up to the presentation, Dr. Yu invited CAC co-Chair Shirley Zhu and other CAC members to attend a meeting of the East-FPN Board and present the work of the CAC.

Asset Mapping and Navigation Initiative Presented by: Susan Selva, Digital Health Lead at ETHP

Another topic of high interest among CAC members was digital health. Members were interested in learning more about the current ETHP asset mapping and navigation initiative. ETHP's Digital Health Lead provided an overview of the development of ETHP's online service directory as well as an overview of the work to support the Ontario Health – HealthCare Navigation Service (HCNS). One of the CAC members is a member of the Digital Health Steering Committee and works alongside staff and other patient and caregiver advisors.

Primary and Community Care Response Teams (PCCRT) Presented by: Mireille Cheung, Director, Primary Health Services at East End Community Health Centre, and Lori Sutton, PCC RT Project Manager

Members of the CAC also had an opportunity to learn more about the PCCRT, an ETHP integrated care planning program. The teams offer neighbourhood- and team-based health and social services care planning to help vulnerable individuals navigate the healthcare system. The program aims to support individuals who don't have a family doctor, may be housebound or have other unmet needs by connecting them with supports and services closer to home. A number of CAC members have also joined some of the PCCRT committees and working groups.



Challenges and Opportunities

Clearly there have been many challenges for everyone working in and receiving healthcare this past year. Service providers experienced unprecedented staffing problems and ongoing pressure dealing with the pandemic. We all felt the absence of caregivers and families in the hospitals and long-term care homes due to COVID-19 restrictions. This further highlights the important role unpaid caregivers play in our health system.

Our patient and caregiver advisors, much like healthcare staff, are experiencing stress and burnout. Two years into the pandemic, CAC members are reporting virtual meetings fatigue. Moving our meetings online has produced a myriad of challenges with access to documents and missed meeting requests related to the use of various IT platforms that are not easily navigated as an external stakeholder. We all agree that the work of the CAC would have benefited from access to an online collaborative space.

Our meeting agendas are always packed as we attempt to maximize the time to provide feedback on initiatives brought forward by ETHP. We struggle to find time in our meetings for discussion and to reflect on the goals and interests of the CAC members. It has been a challenge to cultivate team cohesion – partly due to lack of opportunities to collaborate on initiatives championed by our members.

Advisors are being engaged more and more at every level of ETHP, but like many other patient and caregiver advisors involved in the OHT work, they are trying to find a balance between wanting to engage and realizing they cannot be at every meeting and participate in every discussion. We expect that the demand to engage CAC members will continue to rise as awareness of the value of the CAC grows. While we work to strengthen our internal capacity, it is important to remind ourselves that our work is valuable. What may seem like involvement in many "small things" to our members still produces a cumulative, positive impact in patient engagement in the long run.

With so many competing priorities it is more important than ever that we have a clear understanding of the role that patient and caregiver advisors play in advancing integrated care. Creating opportunities to learn from patients and caregivers will be of critical importance as OHTs roll-out programs and services to counter the devastating effects of the COVID pandemic. Advisors and staff need to work together on a common goal – to ensure meaningful engagement across the OHT.



ETHP has often been identified as a leader in patient and caregiver engagement. As we look forward, there are opportunities for ETHP to continue to be at the forefront of this important work but we will need to be strategic in identifying the resources needed to prioritize and support the work of the CAC and other patient and caregiver advisors across ETHP.

Looking Forward

In the forthcoming period, the CAC will work to achieve the following outcomes:

- 1. Enhanced CAC capacity to deliver on its mandate
- 2. Improved CAC effectiveness
- 3. Increased engagement and community partnership across ETHP

This will be achieved by focusing on:

- 1. CAC skill development
 - Identifying opportunities for training and education of CAC members
 - Continuous learning about engagement best practices
- 2. Ongoing CAC operations and support of ETHP initiatives
 - Seek input from communities that are underrepresented on the CAC through further growth of the CAC membership
 - Continue participation in ETHP committees and working groups to provide the patient and caregiver voice and support ETHP's goals and priorities
 - Collaborate with the PFACs of ETHP partners by instituting quarterly meetings of patient and caregiver advisors across ETHP
- 3. Engagement and co-design
 - Seek input from communities that are underrepresented on the CAC through community outreach
 - Work to improve the CAC engagement webpage to include resources for the community



Get Involved

Interested in learning more about the ETHP Community Advisory Council or how you can become a patient or caregiver advisor?

Contact Nena Pendevska at npendevska@woodgreen.org

We welcome your comments on key aspects of our annual reporting.

Share your feedback on the ETHP Community Advisory Council 2021/22 Annual Report!