

# STEWARDSHIP

**Redefining Leadership and Shaping Health  
Care with Patients, Families, & Caregivers**



Annual Report of the Minister's Patient and  
Family Advisory Council 2023-24

**Ontario** 



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## LAND ACKNOWLEDGEMENT

The Minister's Patient and Family Advisory Council ('Council') acknowledges that our meetings take place on the traditional territory of many Nations, including the Mississaugas of the Credit First Nation, the Anishinaabe, the Haudenosaunee, and the Wendat peoples. These lands, both historically and currently, have been the home and gathering place of many Indigenous peoples from Nations from across Turtle Island.

Long before today, Indigenous peoples have been the stewards of these lands. We acknowledge the Dish with One Spoon Treaty, an agreement to peaceably share and care for the resources around the Great Lakes. Indigenous peoples in Ontario continue to care for this land and shape the province we live in.

The Council stands in solidarity with murdered and missing Indigenous women, girls, transgender, and Two-Spirit people, the children and families tragically impacted by the residential school system, and all Indigenous people impacted by the colonization of Turtle Island.

We humbly demonstrate our respect to the Indigenous peoples of this land, today and all days. We are deeply grateful for the opportunity to live, work, and meet in this territory. We affirm our commitment to heartfelt reconciliation.

## AFRICAN ANCESTRAL ACKNOWLEDGEMENT

The Council acknowledges all Treaty peoples – including those who came here as settlers – as migrants either in this generation or in generations past – and those who came here involuntarily, particularly those brought to these lands as a result of the Trans-Atlantic Slave Trade and Slavery. We pay tribute to those ancestors of African origin and descent.

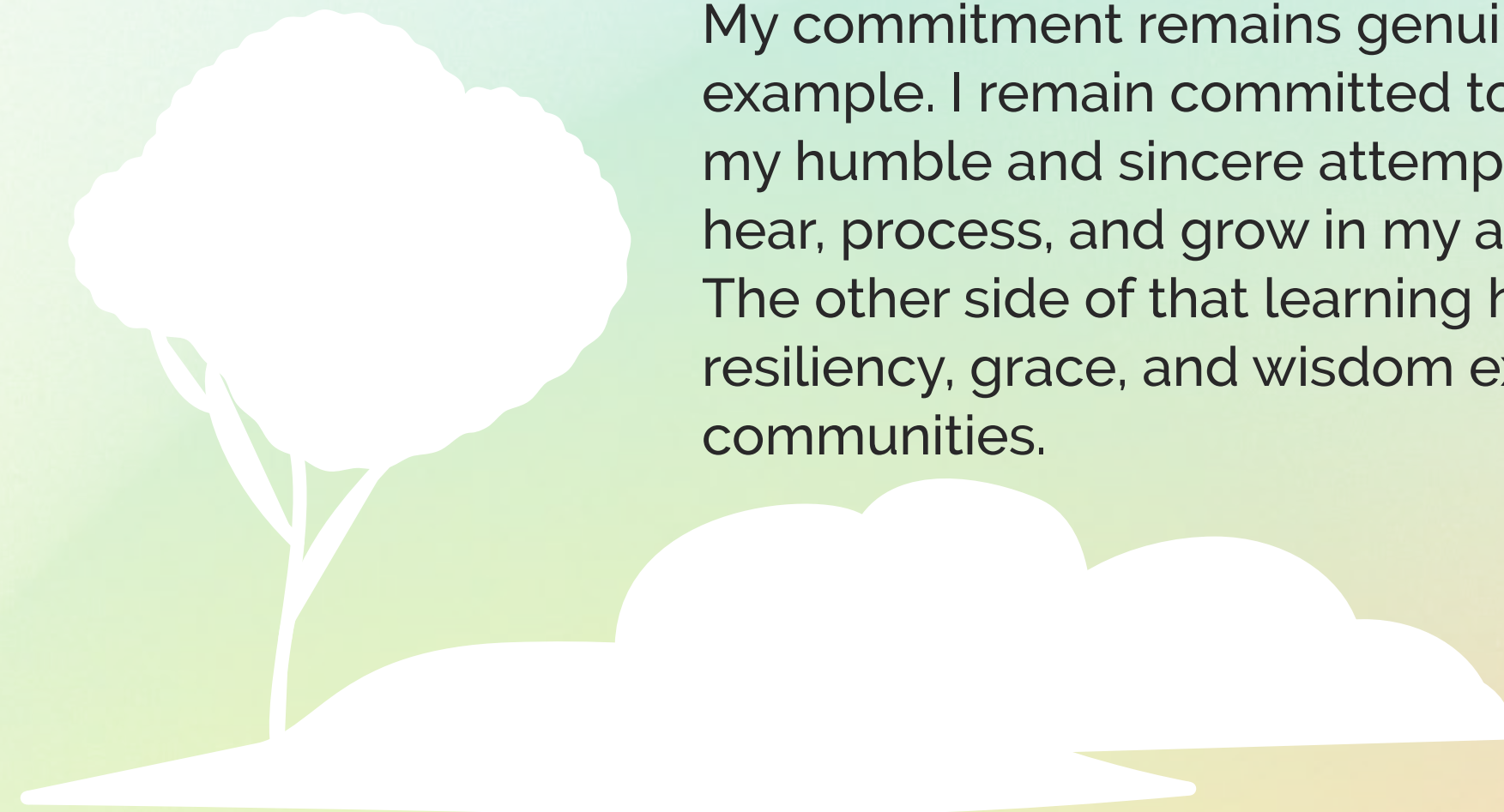




## CHAIR'S RECONCILIATION REFLECTION

In last year's report I stepped out of my comfort zone and provided a personal reflection on reconciliation. I acknowledged my privilege, the Indigenous lands I live on, my ancestry, and the colonial violence that continues to negatively impact Indigenous communities. I also made a commitment that I would be conscious of these colonial harms and continue to learn and grow in my relationship to this land and its Indigenous people, and to work towards unlearning colonial practices.

My commitment remains genuine that I want to lead by example. I remain committed to reconciliation through my humble and sincere attempt to learn, seek, listen, hear, process, and grow in my ability to truly comprehend. The other side of that learning has been to embrace the resiliency, grace, and wisdom exemplified by Indigenous communities.



As a Council, the MPFAC has worked to embed a reconciliation lens in the advice we provide to the Ministry of Health and are learning to build reconciliation into the practices of the Council, starting with personalized discussions that acknowledge the land we share.

This process has helped me to both grow and recognize biases. It has also created more capacity within me to unlearn some of those colonial practices.

As Chair, I recognize that coming from a place of privilege, I have a responsibility to confront anti-Black racism. I am committed to acting in solidarity and partnership with Black communities and seeking to ensure that an anti-racist, culturally diverse, and equitable lens is embedded in all areas of the Council's work.

I will continue to do the work of reconciliation.

**Betty-Lou Kristy**

Minister's Patient and Family Advisory Council Chair





## MESSAGE FROM THE MINISTER OF HEALTH

On behalf of our entire government, I am pleased to accept the annual report of the Minister's Patient and Family Advisory Council for 2023-24. The Council is a strong voice for patients, families, and caregivers, and your lived experience and advice provide valuable insights that are critical to building a patient-centred health care system. Under the leadership of Premier Ford, our government is making record investments to connect people and families to health care across Ontario. [Through Your Health: A Plan for Connected and Convenient Care](#), we continue to make it faster and easier for patients and families to connect to the quality care they need, closer to home.

Over the past year, the Council's work has strengthened the health care system and I am proud of the many accomplishments you have achieved together. The Council has been a strong partner advising on the accelerated implementation of Ontario Health Teams, which are transforming the way people access health care by putting patients at the centre of their care journey. The Council has also played an important role in the development of Youth Wellness Hubs and other vital initiatives to improve health care for all, no matter where they live.

None of this would be possible without the stewardship of the Council's Chair, Betty-Lou Kristy, and the valuable input of all of the Council members. Your voice makes a difference in the lives of the people of Ontario.

Thank you for your incredible dedication to improving patient care for generations to come.

Stay well.

**Sylvia Jones**

Deputy Premier and Minister of Health





## MESSAGE FROM THE DEPUTY MINISTER OF HEALTH

On behalf of the Ministry of Health, it is with deep gratitude that I join Minister Jones in accepting the annual report of the Minister's Patient and Family Advisory Council for 2023-24.

Our ministry has benefited from the contributions of the Council's Chair, Betty-Lou Kristy, and all of the Council's members. To Abbey, Amandeep, Betty-Lou, David, Dean, Don, Joan, Karen, Sandi, Sandra, Shannon, Shequita, and Wendy, as well as to our outgoing members Kimberly and Sterling – thank you.

Your advice, drawn from your lived and living experiences, has enriched many aspects of our work and we are committed to strengthening our partnership going forward. Your voices matter, and the impact your voices have is deeply valued.

As a cancer survivor, I know firsthand that our health care system can feel complex. I also know there are so many incredible people, including the Council, that are working to improve patient outcomes and the experiences of all patients, families, and caregivers in Ontario. I recognize the critical role each member of the Council plays to support our shared work of building a patient-centered health care system.

Thank you for your continued passion, resilience, and expertise. You inspire us all.

Warmest regards,

**Deborah Richardson**  
Deputy Minister of Health





## MESSAGE FROM THE CHAIR

Let me start with an honest reflection – it's challenging to be part of a disruptive, yet needed, health care transformation. Particularly as we continue to recover from the pandemic and with disparities, inequities, and barriers in the system in full view. I would not be true to myself if I did not also mention soaring mental health and substance use concerns, toxic unregulated drug supply, and the impact that being unhoused has on overall wellness. This all underscores the importance of our work and the vision for meaningful change.

What has been particularly challenging – but also inspiring – is the drive to humanize the health care system. Much of that change continues to be driven by the tireless efforts of lived/living experience partners, patients, families, and caregivers themselves. Those who have experienced marginalization or harm within the system hold a wealth of knowledge to contribute to creating a more equitable and safer space for all.

I want to recognize that many individuals, providers, and systems across Ontario are working hard to deliver this transformation and are sincere in recognizing that health and social care must centre around the people receiving

services, along with their families and caregivers. It's absolutely imperative that this transformation is shaped and implemented in partnership and co-design with those with lived/living experience.

This movement to centre the needs of patients, families, and caregivers and equitably partner with them in system design is still relatively new as a full-scale priority. The vision is there, and the work is advancing. Now, we are going through the growing pains of implementation.

This brings me to the title of this year's report: **"Stewardship: Redefining Leadership & Shaping Health Care with Patients, Families, & Caregivers"**.

I think of stewardship as a unique type of collective leadership but also a mechanism for shared responsibility and collective action. Stewardship requires innovation, learning and knowledge sharing, empowerment, resiliency, and adaptability to sustain our drive towards a healthier future. Stewardship is enabled when we work together to build and sustain trust and relationships. Stewardship is exemplified when authentically empowering, involving, partnering, and co-designing with our lived/living experience partners, patients, families, and caregivers.



## MESSAGE FROM THE CHAIR

This year, the work of the Council has demonstrated stewardship through leading by example to show the successes that are possible when working together with patients, families, and caregivers to impact system change.

I would like to thank the Honourable Sylvia Jones, Deputy Premier and Minister of Health, for her continued support, trust, and time. In one of our regular meetings, Minister Jones shared some advice that really stuck with me. The Minister said, "Betty-Lou, don't forget to take some time to celebrate the successes."

You will see these success stories reflected in this year's report. The work of the MPFAC is a key example that there really is bold movement and there has been incredible growth within the health care system. Recognizing this success helps renew collective determination to see our work through to completion, though we may be exhausted. Being a good steward in a time of change means celebrating successes, acknowledging struggle, and continuing the journey.

I would also like to express my gratitude to the Council for their extensive contributions to improving the patient, family, and caregiver experience in Ontario. I am humbled by their remarkable expertise, diversity of wisdom and perspectives, passion, and determination. We learn from each other. We authentically respect each other. We have grown in our expertise and collective skills because we share space and hold each other in unconditionally high regard.

**Betty-Lou Kristy**

Minister's Patient and Family Advisory Council Chair



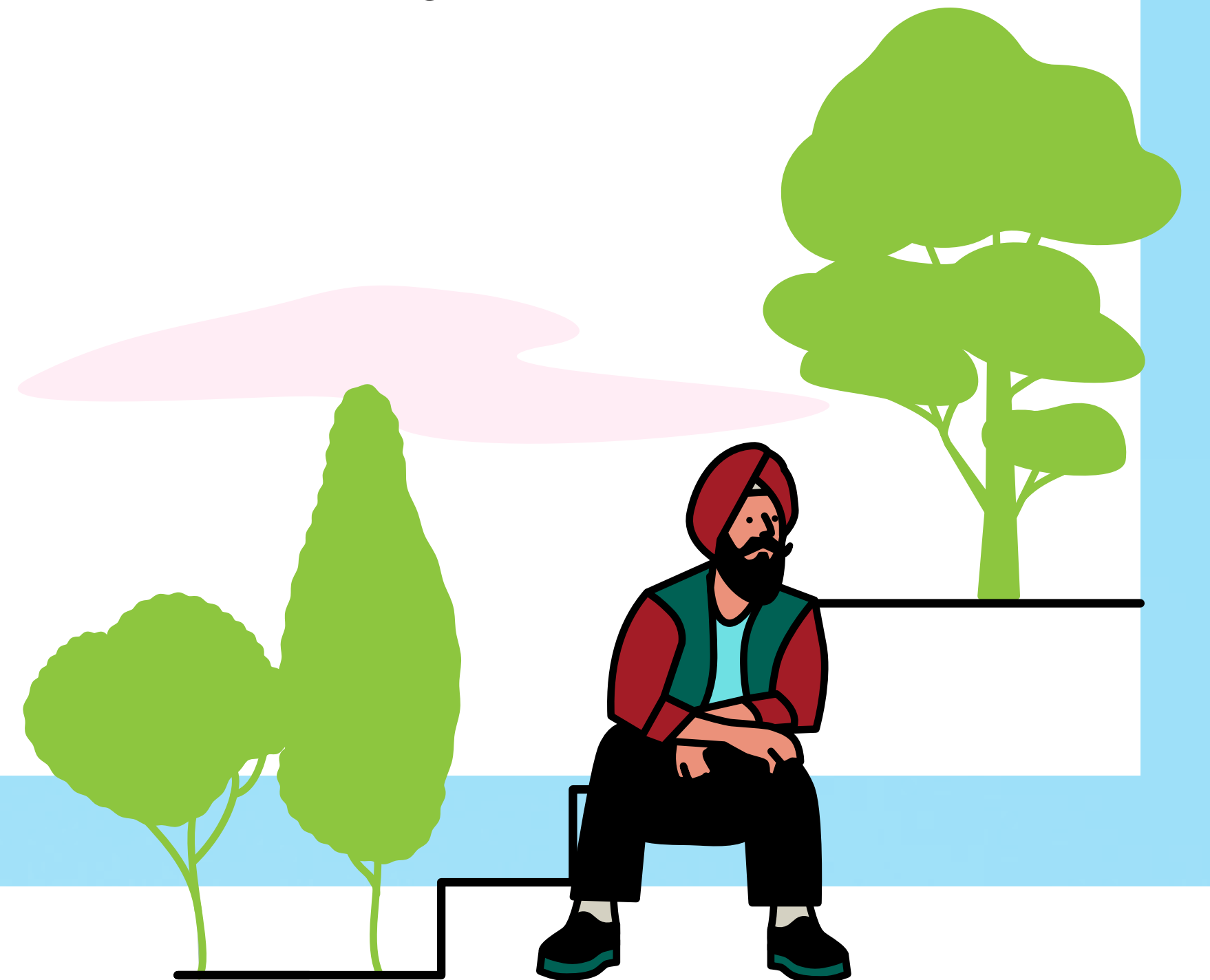


## THANK YOU TO MY TEAM

I want to thank the Patient Engagement team at the Ministry of Health, which supports me as Chair. There is an incredible amount of work, coordination, and expertise that happens behind the scenes. My impact as Chair is in large part due to this incredible team. They are my biggest supporters in so many ways. Allison, Jessica, Chris, Michelle, and Sophia have been such a phenomenal support system for me, both personally and professionally, in this role. No matter what I need, or how far I vision, they always work hard to land that for me. To say that I am grateful would be an absolute understatement.

## INCLUSIVE LANGUAGE

In this report, the term 'patient' is inclusive of those who identify as a client, citizen, resident, community member, those with lived/living experience, and any others who may interact within the health care system. The terms 'family' and/or 'caregiver' are inclusive of people who provide support and care, whether that be as part of a biological family, a self-identified family, as an informal caregiver, or as a friend.







## OVERVIEW OF THE COUNCIL

The Minister's Patient and Family Advisory Council ('Council') is a provincial advisory body to the Minister and Ministry of Health ('ministry') with a mandate to help improve patient care by ensuring the voices of patients, families, and caregivers are at the centre of policy development and decision-making. The Council is currently made up of 12 members, plus the Chair.

Over the past year, the Council demonstrated the value of engagement as stewards of an innovative and integrated health care system. In 2023-24, engagement with the Council has grown by 75%<sup>1</sup> across the ministry, including new program areas seeking patient, family, and caregiver advice.

The Council engaged on several important focus areas this year, including Ontario Health Teams, digital health and virtual care, home and community care, mental health and addictions, primary care, health care capacity planning, integrated community health services, and other strategic initiatives. The expansion of Council engagements has allowed the impact of the Council to be felt across the health system in Ontario.

The success of the MPFAC stems from the breadth of expertise and the lived/living experience of its members and Chair, which span many areas of the health system and represent a diverse range of voices and perspectives. Drawing from their expertise, the Council provides valuable advice to inform the ministry's development and implementation of strategic health priorities.

### **Council Snapshot: Lived/Living Experience and Expertise**

The Council demonstrates leadership and stewardship in the health system through their work with the ministry as well as the work they do as individuals in their local communities.

<sup>1</sup> This percentage growth refers to the number of topics the Council engaged on. This number increased from 8 engagements sessions in 2022-23 to 14 sessions in 2023-24.



## COUNCIL SNAPSHOT: LIVED/LIVING EXPERIENCE AND EXPERTISE



**Betty-Lou Kristy (Chair)**

Childhood Trauma, Domestic Violence, Substance Use/Addiction, Mental Health, Bereavement, Cancer, Chronic Disease, Restorative Justice, Peer Support, Housing, Governance, Engagement and Co-Design



**Abbey Hunter**

Northern Communities, Chronic Disease, Youth Perspective, Active in many projects and advisory groups in hospitals and her local OHT



**Amandeep Kaur**

South Asian Community, Substance Use/Addiction, Mental Health, Marginalized and Diverse Populations, Equity and Inclusivity, Leadership, Strategic Visioning, Community Development, Health Promotion, Chronic Disease Prevention



COUNCIL SNAPSHOT: LIVED/LIVING EXPERIENCE AND EXPERTISE



**David Bell**

Family Caregiver Mental Health, Child Health Services, Care for Medically Fragile Children, Pediatric Palliative Care, Research Ethics



**Dean Valentine**

Veteran of Canada's Royal Canadian Navy, HIV/AIDS, Mental Health, Substance Use/Addiction, Neurocognitive Disorder, Harm Reduction, Peer Support, Community Engagement, Governance, Research, 2SLGBTI+ Advocacy, Community Health Co-design



**Don Mahleka**

Refugee from Zimbabwe, Chronic Pain, Trauma, Mental Health, Health Equity, Anti-Racism, Anti-Oppression, Youth Program Development, Change Management, Participatory Research, Policy Development



**Joan Duke**

Northern Communities, Supporting Family/Caregivers, Support and Protect Seniors, Chronic Conditions, Advisory & Empowerment, Community Engagement and Volunteer Work, Empowerment of Seniors and People with Disabilities, Inclusion of Equity, Equality and Diversity, Virtual Care, Digital Health, Policy Review



COUNCIL SNAPSHOT: LIVED/LIVING EXPERIENCE AND EXPERTISE



**Karen Samuels**

Child Protection Worker, Cancer Survivor, Mental Health and Addictions, Youth Engagement, Homelessness, Human Trafficking, Emotional Intelligence, Immigration, Kinship Services, Equity, Diversity, Peer Support



**Sandi Bell**

African-Canadian/Indigenous, Human Rights, Social Justice, Anti-Racism, Anti-Oppression, Mental Health, Child Welfare, Education, Youth, Accessibility, Disability Issues, Equity, Diversity, Access, Inclusion, Mediation, Training



**Sandra Holdsworth**

Transplant Recipient, Organ and Tissue Donation, Chronic Disease Management, Mental Health, Social Determinants of Health, PTSD, Home and Community Care, Diabetes, Palliative Care and End of Life, Research, Co-Design, Knowledge Translation, Engagement, Leadership, Patient Partnership, Quality Improvement, Training



**Shannon McGavin**

Over 25 Years in Education Field, Rural Communities and Integrated Care, Youth and Community Wellness, Mental Health and Substance Use, System Change, People Centred Teams, Research, Health Standards, Engagement and Co-Design, Change Management, Community Development, Social Determinants of Health, Quality Improvement, Equity, Diversity, Inclusion and Belonging, 2SLGBTQI+ Advocacy

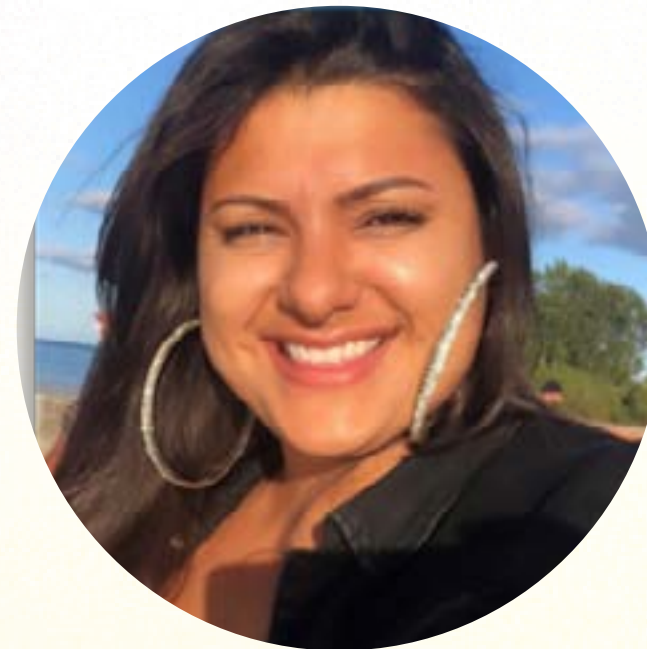


COUNCIL SNAPSHOT: LIVED/LIVING EXPERIENCE AND EXPERTISE



**Shequita Thompson-Reid**

Racialized Communities, Equity and Anti-Oppression, Anti-Black Racism, Trauma, Mental Health, ADD/ADHD, Youth Engagement, Housing, Conflict Mediation, Violence Prevention, LGBTQQIP2AA, Education



**Wendy De Souza**

Intersectional Feminist Lens, Equity, Decolonizing Institutional Spaces, Gender Based Violence, Human Trafficking, Research, Complex Birth Issues, Mental Health and Addiction, Two Spirit, Nonbinary and Trans Communities





# BY THE NUMBERS

## THE COUNCIL CHAIR ENGAGEMENTS:

The Council engaged  
**36 TIMES**  
with the ministry and health  
system partners, spending  
**751 HOURS**  
partnering to shape the  
ministry's health policy  
and programs<sup>1</sup>.

**10 meetings**  
with the Minister and  
senior ministry leadership  
working on collaborative  
partnership and  
co-design.

**26 hours**  
meeting with the  
ministry to support  
the work of the Council  
and provincial patient,  
family, and caregiver  
engagement  
activities.

**4 specialized mentorship**  
sessions with Ontario  
Health Teams to advance  
the work of patient,  
family, and caregiver  
engagement  
locally.

**Over 80 hours**  
of strategic advice  
through health system  
working groups  
and speaking  
engagements.

**In 2023-24,**  
Council engagement has  
grown by 75%<sup>2</sup> across the  
ministry, including new  
program areas seeking  
patient, family, and  
caregiver advice.

<sup>1</sup> Note the total numbers of hours the Council spent partnering to shape ministry health policy and programming includes preparation time and meeting time.

<sup>2</sup> This growth refers to the number of topics the Council engaged on. This number increased from 8 engagements sessions in 2022-23 to 14 sessions in 2023-24.



# BY THE NUMBERS

## THE COUNCIL'S SELF-EVALUATION DEMONSTRATED THAT:

**96%  
of members**

feel that they are engaged and involved in the work of the ministry as a result of their participation on the Council.

**90%  
of members**

feel that there is an effective feedback loop between the ministry and the MPFAC.

**90%  
of members**

feel that their work makes a difference to the work of the ministry and 86% are confident that the ministry takes the feedback provided by the Council into consideration.

**88%  
of members**

understand how their input impacts ministry programming and policy.

**90%  
of members**

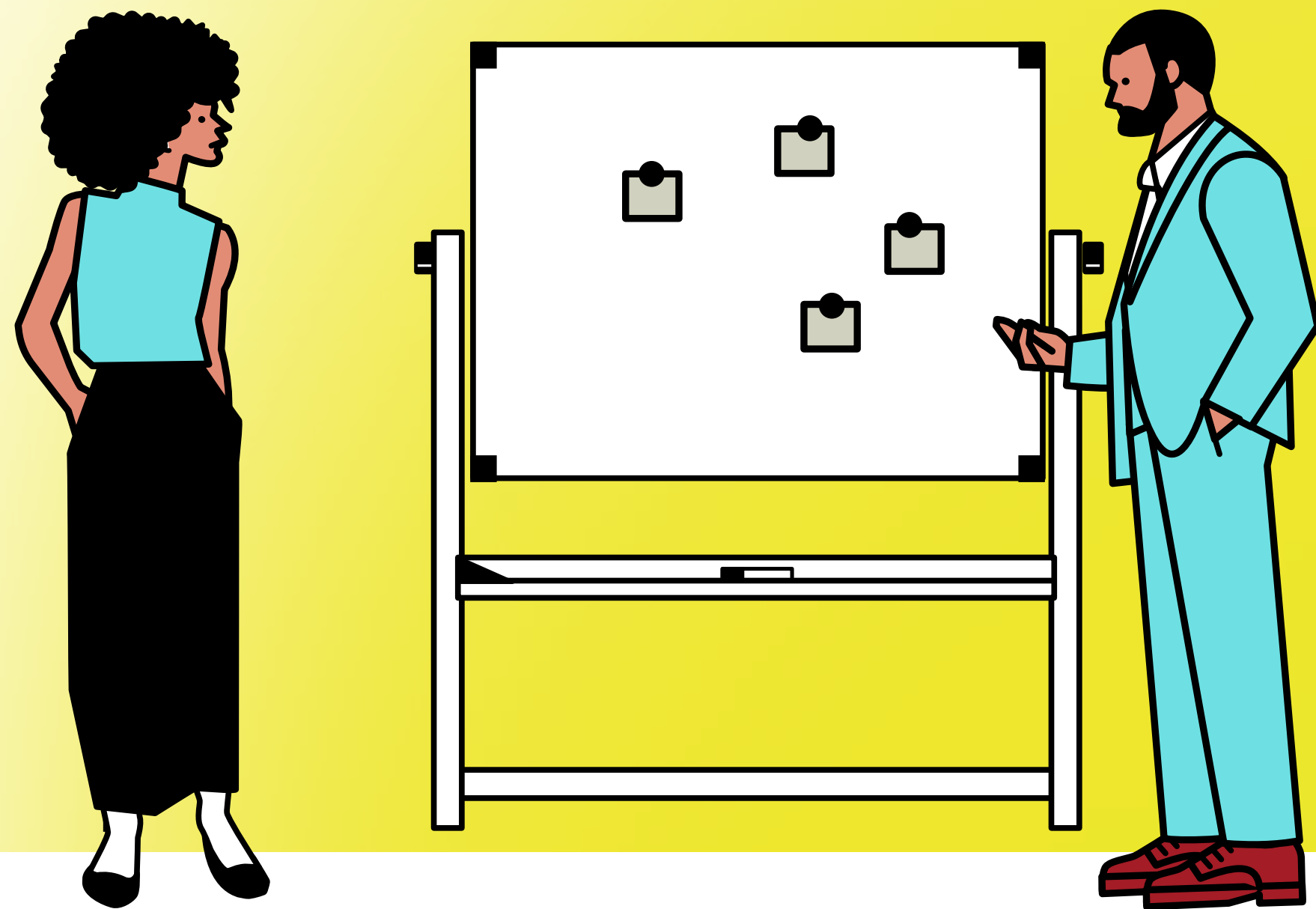
feel that a safe, inclusive, and trauma-informed space is established for Council meetings.

**96%  
of members**

feel that they have the supports they need to be engaged as part of the Council.



# SUSTAINING COUNCIL ENGAGEMENT AND PARTNERSHIP



## OVERVIEW

In 2022-23, the Chair and members undertook a self-evaluation of their engagements with the ministry leveraging the help of the [Public and Patient Engagement Evaluation Tool](#). Through this process, the Council confirmed an interest in sustaining and expanding engagements with the ministry, including broadening topics for engagement. They also expressed an interest in improved transparency about how their advice is used by the ministry, including through frequent feedback loops with the Council.

In 2023, the Chair co-led a working group to develop the [Creating Engagement Capable Environments within Ontario Health Teams](#) framework. The Council also had the opportunity to provide advice to support the framework's development. This framework offers Ontario Health Teams (OHT) a roadmap to maturing their patient, family, and caregiver engagement activities by outlining competencies, supports, and enablers for successful engagement. Through engagement on this framework, the Council and Chair supported stewardship of patient, family, and caregiver engagement and partnership within OHTs.

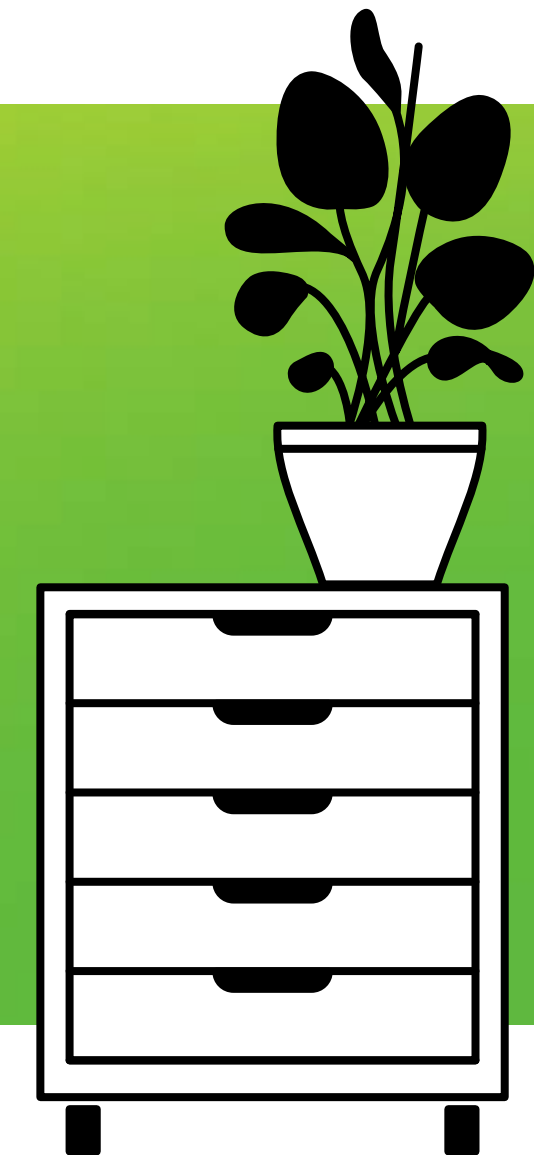


## IMPACT

The Council has impacted patient, family, and caregiver engagement and partnership activities both within the ministry and for patients, families, and caregivers involved with their local OHT.

In 2023-24, the Council engaged with ministry program areas on a number of new topics, increasing the impact of patient, family, and caregiver perspectives in health system priorities. In addition, in consideration of Council feedback, the ministry standardized the process to capture Council feedback and report back to the Council on the impact of their advice. Council members have strengthened their advocacy for ministry programs and initiatives to demonstrate how equity, diversity, and inclusion is considered and advanced. This year, the MPFAC Annual Report highlights the ways the Council has championed equity, diversity, and inclusion in all its work with the ministry.

Within the health system, the Council has supported stewardship of patient, family, and caregiver engagement within OHTs through their contributions to the development of the [Creating Engagement Capable Environments within Ontario Health Teams](#) framework. As a requirement of the newly announced multi-year implementation funding, OHTs must adopt and implement this framework with the goal of advancing patient, family, and caregiver partnership and engagement practices across OHT planning and operations and reduced barriers to equitable participation.





# OHT ACCELERATION AND HOME CARE MODERNIZATION



## OVERVIEW

The Council provided advice on the ministry's plan to accelerate Ontario Health Teams (OHTs) and proposed requirements for an OHT to be designated under the Connecting Care Act. They noted that partnership and co-design with patients, families, and caregivers is fundamental to advancing more equitable and integrated systems. The Council recommended that patient, family, and caregiver partnership be embedded in structural and clinical priorities of OHT acceleration. The Council also emphasized the importance of clear communication with OHTs and the need to consider equity and community involvement in OHT designation requirements.

The Council also consulted on the ministry's work to transition Home and Community Care Support Services to Ontario Health atHome. The Council noted the importance of uninterrupted service and clear communication with clients and families on how they will continue to access care.

The Council also provided advice on home care leading projects led by seven OHTs. They recommended building patient, family, and caregiver engagement into new models. The Council noted the importance of effective health human resources in home care delivery and recommended ongoing recruitment incentives and supports for families and caregivers to deliver care at home.

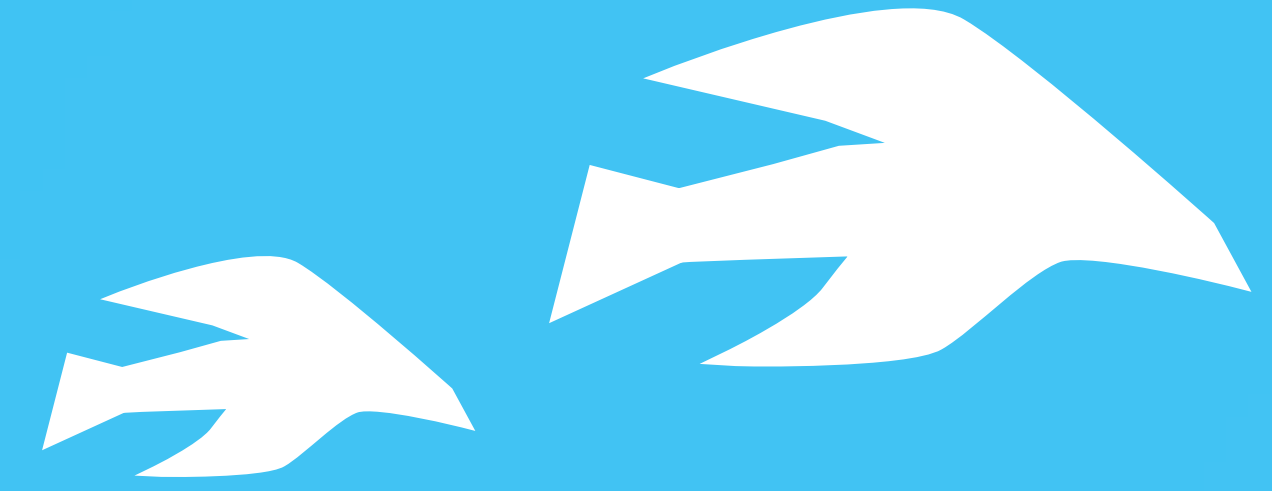


## IMPACT

The ministry recognizes the importance of patient, family, and caregiver involvement in OHTs. The draft OHT designation regulation includes proposed requirements to standardize patient, family, and caregiver involvement structures within OHT governance. The ministry and MPFAC Chair also continue to work with OHT support partners to provide tools and resources for OHTs to strengthen patient, family, and caregiver engagement and partnership.

The ministry continues to reflect on timing and planning requirements to prevent care disruption. The ministry will ensure timely and effective communication with patients, families, caregivers, and other partners about Ontario Health atHome and ongoing access to home care services.

Engagements with the Council have helped the ministry to further explore how the needs of patients, families, and caregivers can be built into home care models.



“ The Council's perspectives and insights on expanding models of care, standardizing the quality of home care delivery, and communicating with patients and caregivers has helped us as we further our work in modernizing the home and community care sector and creating a more integrated health care system through the establishment of Ontario Health atHome. Our team values the opportunity to work with the Council members, where their meaningful contributions towards home care policy development, implementation and modernization continues to positively shape the ministry's work.”

**– Amy Olmstead, Director, Home and Community Care Branch**





“ The ministry made substantial progress on OHT implementation this year, including by identifying 12 OHTs to accelerate towards designation, releasing guidance on Primary Care Networks in OHTs, and developing OHT designation regulation criteria. The Minister’s Patient and Family Advisory Council’s continued partnership and insights have been critical to the development of this work. It is a true pleasure to work alongside Council members and witness their passion and stewardship to improve coordinated care for patients. The Council’s unwavering dedication to equity and their committed partnership on OHT implementation is a critical input to the success of OHTs – thank you.”

**– Allison Costello, Director, OHT Policy and Operations Branch**

## EQUITY AND INCLUSION CONSIDERATIONS

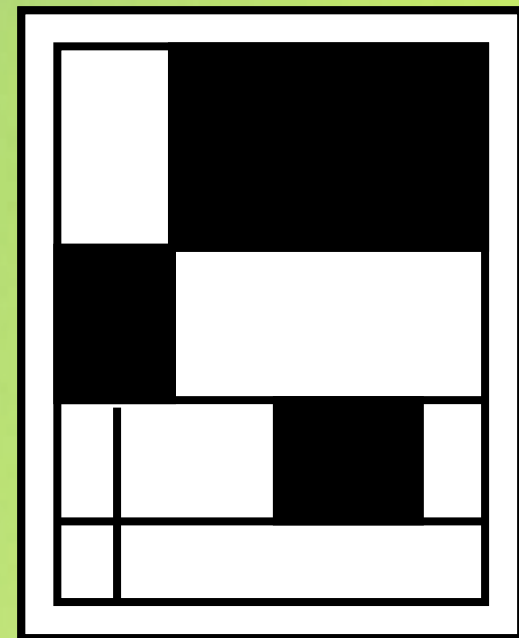
The Council highlighted the importance of partnering with their local community as OHTs work towards designation. Council members recommended measuring performance related to equity and establishing a high level of transparency and trust with community members and patients, families, and caregivers.

The Council underscored the importance of equitable and consistent access to home care services across the province, including in underserved communities, rural and northern areas. They noted that flexibility in home care plans could help contribute to overall patient, family, and caregiver well-being.





# DIGITAL HEALTH AND DATA INITIATIVES



## OVERVIEW

The Council was engaged on digital health initiatives focused on making it easier for providers and patients, families, and caregivers to access reliable health information and to communicate among patients, families, and caregivers and their health care providers.

The Council was supportive of secure messaging between patients and their physicians and identified the need to ensure access to technology is equitable, including through accessibility and available languages and modalities. The Council recognized that while the ministry pursues virtual options, maintaining in-person care options based on patient preference and needs is important.

The Council provided advice on opportunities to standardize patient summaries that avoid patients needing to retell their health care journeys. The Council noted the importance of involving patients, families, and caregivers in this process to ensure summaries are up-to-date and include all partners in care, including specialists and mental health and addictions service providers. Council members noted that patients should have more access to and control over their personal health information available on digital records platforms to protect their privacy.

Several Council members were also engaged in the Civic Engagement Strategy working group sponsored by the Ontario Health Data Council (OHDC), which advised on a civic engagement approach for health data in Ontario. The working group developed recommendations for a provincial civic assembly model and the OHDC has shared these with the Ministry.

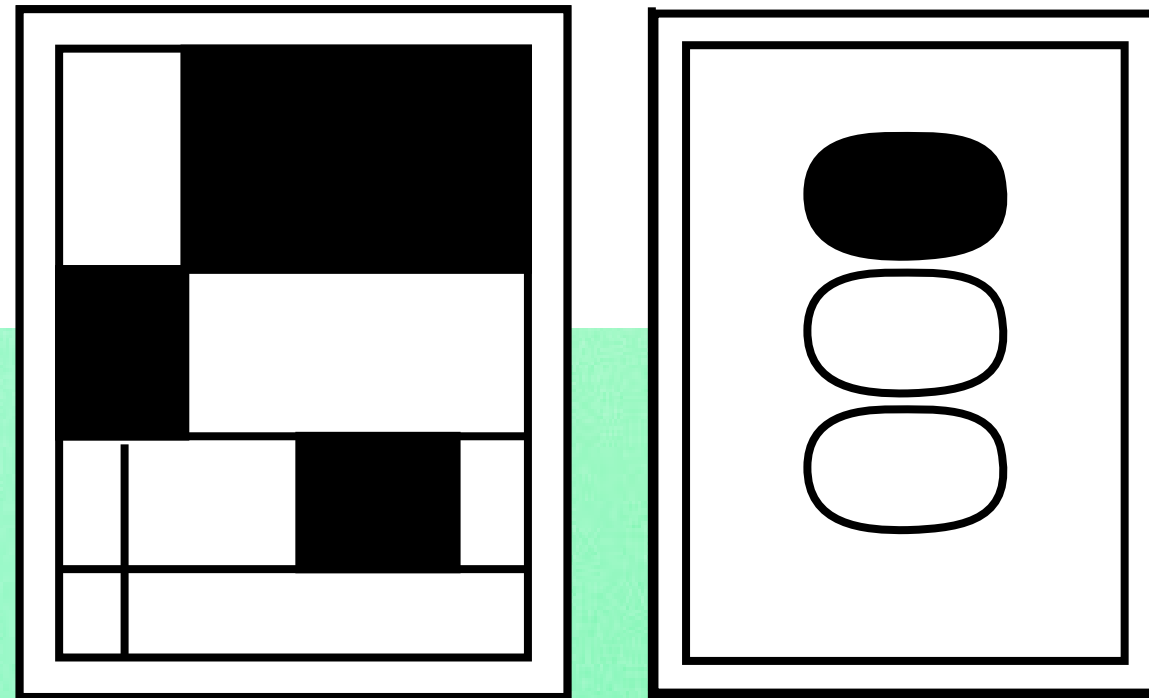


## DIGITAL HEALTH AND DATA INITIATIVES

**IMPACT**

The ministry has committed to ensuring the feedback and input received from the Council is incorporated into the ongoing work with Ontario Health to evaluate proposed models of secure messaging, develop a standard approach for patient summaries, and report back to the Council on progress.

The Council has pointed to the Civic Engagement Strategy working group as a leading example of co-design with patients, families, and caregivers in policy development. The ministry is applying learnings from this approach to its partnership with the Council.



“ The ministry applauds the Council's ongoing commitment to Digital and Data. Their passion, insights, and lived experiences are a constant source of inspiration and they keep us focused on achieving a patient-centric, data-driven, digitally-integrated health care system that will benefit all Ontarians.”

**– Michael Hillmer, Assistant Deputy Minister, Digital and Analytics Strategy Division**

**EQUITY AND INCLUSION CONSIDERATIONS**

The Council indicated that when developing digital health and data programs, it is important for communication to patients, families, and caregivers to be planned and delivered in a culturally appropriate manner. The Council noted the need to develop community-specific plans to address the diverse and unique needs of each community. Council members also highlighted that unequal access to emerging technologies and devices may exacerbate gaps and health inequities due to their related cost. They recommended that in-person services should be maintained to support individuals who may benefit from this care option, including seniors and newcomers.



# SYSTEM PLANNING AND ACCESS TO CARE

“ Consultation with the Council provided the ministry’s team with valuable insights, observations, and a true patient perspective. With the Council’s input and advice, Accreditation Canada was able to enhance the people-centered care standards for all Ontarians visiting community surgical and diagnostic centres.”  
– **Laura Pinkney, Director,  
Health Insurance Branch**

## OVERVIEW

The Council engaged on health system planning by considering factors that impact the health care workforce and enablers to improve service delivery. The Council identified opportunities that included ensuring caregivers can access supports and programs, supporting easier access to care where people live, better care coordination, and enhancing supports for health care providers. The Council also emphasized prevention and the importance of applying equity and co-design principles with patients, families, and caregivers to inform these opportunities.

The Council provided their lived/living experience and expertise regarding access to interprofessional primary care in their local communities. The Council emphasized opportunities to work across primary care and mental health and substance use/addictions care providers, provide more information on how to access services and what is available, and the need to embed equity, cultural safety, and social determinants of health in primary care.

The Council has continued to be engaged in the ministry’s plan to implement Integrated Community Health Services Centres. The Council provided strategic advice to inform Accreditation Canada and the ministry’s development of a strengthened quality assurance program and the development of quality standards for these centres. The Council encouraged Accreditation Canada develop quality standards that promote cultural competency, accessibility, and patient privacy.



## SYSTEM PLANNING AND ACCESS TO CARE

**IMPACT**

The ministry has benefited from the lived/living experience and expertise of the Council to inform interprofessional primary care, and health system planning and its impacts on the health care workforce.

The ministry and Accreditation Canada are reflecting on the Council's advice to inform the development of strengthened quality standards for Integrated Community Health Services Centres and have committed to ensuring patient-centered care is built into the quality and safety standards that are applied to these centres.

" I am grateful for the Council's advice on opportunities to enhance patient, family and caregiver experiences across the health system. The perspectives shared by the Council reinforce the importance of ensuring access to care for all, delivering care at or close to home, appropriately using digital tools to support patients and providers, and creating a more diverse health workforce. These insights have informed our planning work and I look forward to further engagement with the Council in the future."

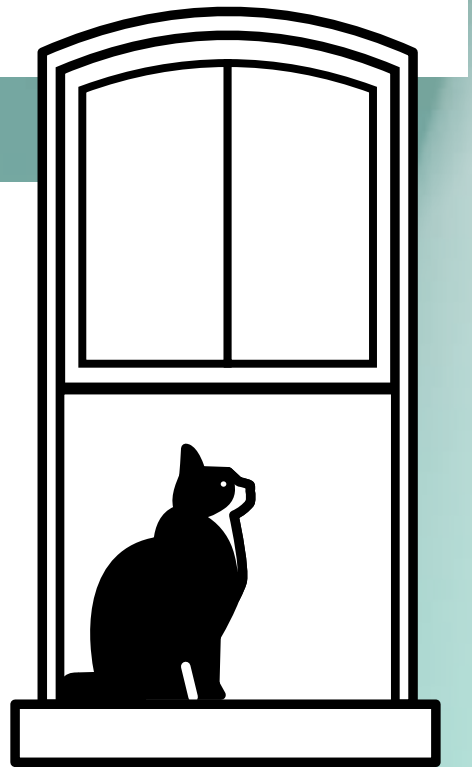
**– Dr. Karima Velji, Chief of Nursing and Professional Practice & Assistant Deputy Minister.**

" The ministry appreciates the ongoing work, input and partnership of the Minister's Patient and Family Advisory Council in improving Ontario's primary health care sector. The voices of patients and caregivers are an essential part of creating a health care system that meets the need of all Ontarians and respects the lived experience of those that access our publicly funded health care system."

**– Nadia Surani, Director, Primary Health Care Branch**

**EQUITY AND INCLUSION CONSIDERATIONS**

As the ministry advances health system planning, the Council highlighted a need to build culturally competent care, address the social determinants of health that impact patient access to care, and to plan for accessibility and local community needs (e.g., language). The Council also emphasized the importance of involving patients, families, and caregivers, including those from equity-deserving groups, to support the development of interprofessional primary care teams.





# SHAPING ONTARIO'S MENTAL HEALTH AND ADDICTIONS LANDSCAPE

## OVERVIEW

The ministry has been working with Ontario Health to develop programs to ensure people have access to the care they need, when they need it. One example, being led by Ontario Health's Mental Health and Addictions Centre of Excellence (MHA CoE), is the development of Substance Use Disorders Integrated Care Pathways for people presenting in Emergency Departments, connecting them to the care that meets their needs. Research and stakeholder engagements identified the need for expanding the substance use integrated care pathways to address gaps in the continuum of care.

The Council advised that integrated care pathways for substance use disorders should include considerations for the needs of young people. The Council noted that harm reduction, care transitions, peer support and navigation should also be considered in integrated care pathways. Council members stressed the need to address negative stigma surrounding those who use substances as a critical success factor for this integrated care pathway. They also advised that public education, data-driven approaches, coordination amongst care providers, and partnerships with community services and groups all serve as opportunities to improve care access and health outcomes.



## IMPACT

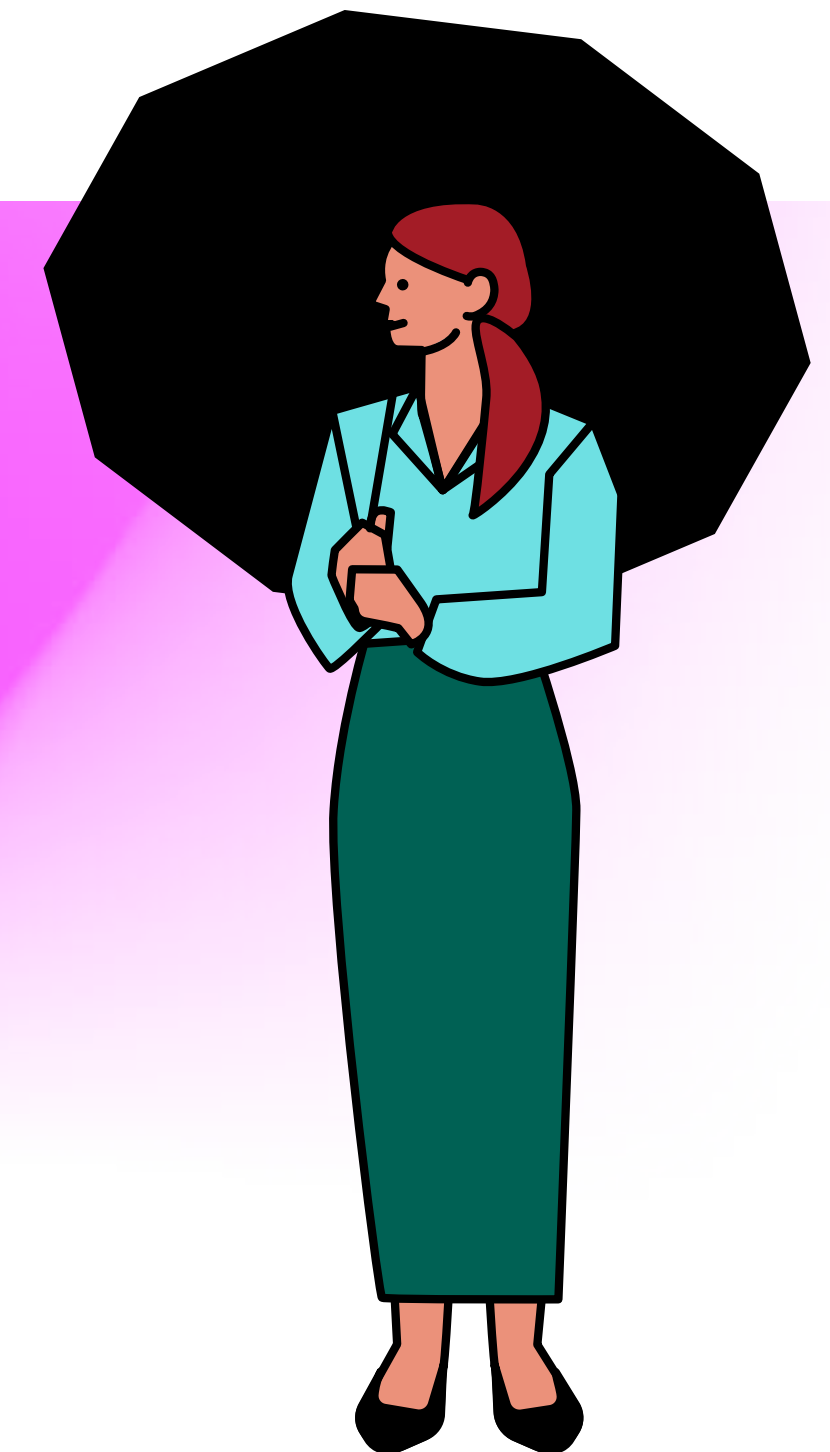
The MHA CoE is leveraging the input provided by the Council to inform program expectations for the Substance Use Disorders Integrated Care Pathways. Recognizing the importance the Council placed on destigmatizing care delivery for substance use, the CoE identified that a large focus of this work will be supporting sector change through education and training, and providing resources needed to enable the provision of quality, evidence-based, respectful, compassionate, and trauma-informed care.

## EQUITY AND INCLUSION CONSIDERATIONS

The Council shared their lived/living experience and expertise on the harms and trauma when seeking care for substance use/addictions and emphasized the importance of communication using destigmatizing language, delivering care that is trauma-informed and culturally safe. The Council recommended that integrated clinical care pathways involve community organizations to help in de-stigmatization efforts and promote dignity for individuals.

“Our engagement with the Minister’s Patient and Family Advisory Council offered valuable insights into the critical need to address stigma for people who use substances. The Council’s input reinforced the importance of the Substance Use Disorders Integrated Care Pathway work for people who use substances, particularly the focus on peer support and considerations that are important for successful care transitions. The team at the MHA CoE is grateful to the Council for their advice and their support for this important work.”

**– Dr. Paul Kurdyak, Vice-President, Clinical, Mental Health & Addictions Centre of Excellence, Ontario Health**





# CHAIR'S OPPORTUNITIES AND CLOSING REMARKS



As Chair, I am so excited by the work of the Council. I want to shine a light on the impact that is made when patients, families, and caregivers are involved in improving the health care system. I also want to inspire and encourage leaders across the health system that we are continuing to transform as a system – we are not done yet. I know that while there are successes to be proud of, more work is needed to address gaps in unmet health and social needs and the harms of stigma, bias, and discrimination.

I've learned that it's about balance, considering all perspectives, and working together to build a healthier system of care. It circles back to stewardship – shared stewardship at all levels of the health care system. And requires a great deal of personal resolve and awareness. Knowing when to step back in wisdom and when to step forward in determined action.

As I think about my recommendations, I continue to feel called to support action for strong partnership and co-design with patients, families, and caregivers. It is my passion and my purpose. I think that is a reality for all of us who are driving transformation from the perspective of lived/living experience and expertise. It can be both rewarding and triggering all in one breath – particularly for those of us who have been harmed and/or who have lost loved ones.

But I definitely feel that we have arrived.



## CHAIR'S IDENTIFIED OPPORTUNITIES FOR 2024-25



1. **Embody stewardship** in patient, family, and caregiver partnership, engagement, and co-design. Lead by example to drive genuine trust, respect, collaboration, transparency, and empowerment in health system partnerships.
2. **Demonstrate accountability** for partnership and co-design with patients, families, and caregivers. Measure key performance indicators linked to impacts of patient, family, and caregiver involvement, particularly with those from equity-deserving groups.
3. **Continue to build** the practice of co-design with patients, families, and caregivers into the foundation of health system transformation.

4. **Embed equity and inclusion** and facilitate trauma-informed safer spaces for patients, families, and caregivers to be partners in health system transformation.

5. **Prioritize bold and innovative policies** to address barriers and champion equitable and meaningful partnership with patients, families, and caregivers at all levels of system planning, care design, and implementation.

6. **Strengthen resources and structures** to drive meaningful partnership with those who have experienced harm, discrimination, stigmatization, and marginalization within the health care system, including Indigenous, Black and racialized communities, people with mental health, substance use and addictions concerns, people with disabilities, newcomers, Francophone, and LGBTQ2S+ communities.



APPENDIX

# COUNCIL MEMBER BIOGRAPHIES







## BETTY-LOU KRISTY

Betty-Lou Kristy is a bereaved mother, in recovery for close to 25 years from alcohol/multi-drug addiction, substance use disorder, trauma and mental health issues. She lost Pete, her 25-year-old son with concurrent disorders, to an accidental opioid overdose in 2001. She has additional caregiver experience in supporting close family members with cancer, cardio, lung/COPD, diabetes and asthma.

Humanizing the health care system, improving quality of life and reduction of harm are among Betty-Lou's top priorities. She has spent almost 20 years working within the Ontario health care system as a lived experience and family advisor, educator and advocate. In this capacity she has helped to frame policy, governance and programming. Before this journey, her background was in corporate marketing. Betty-Lou has over 15 years of extensive board governance training and experience. She is the Director of Support House's Centre for Innovation in Peer Support and

has also received several awards such as the Centre for Addiction and Mental Health Transforming Lives Award, the Ministry of Health and Long-Term Care Achievement, Commitment and Excellence Award – Partner Relations for her work with the Expert Working Group on Narcotic Addiction and the Support House Employee of the Year Award. The Centre has been awarded the Ontario Peer Development Initiative Innovators Award, AMHO President Shield Award and the Association of General Hospital Psychiatric Services Celebrating Innovation Award.





## ABBIEY HUNTER

Abbey was born and raised in beautiful Thunder Bay, Ontario and is currently in the fourth year of her Honours Bachelor of Political Science at Lakehead University. At 16 years old she experienced the negative parts of our healthcare system, specifically the shortcomings in Northern Ontario, to which she has become an advocate for better access and support in the North. After a near-death experience and being airlifted to London Ontario, she was diagnosed with Lupus. Following her diagnosis and searching for an outlet to cope with her disease, she became a Patient Family Advisor at the Thunder Bay Regional Health Sciences Centre, advocating from a younger patient perspective. From there, she began doing talks with nursing students and health care professionals, sharing her story and pushing for thorough and quality care for young people in the health care system. From there she sat on the Women and Children's Program and the Telemedicine Program, pushing for both younger

advocacy and the importance of telemedicine in the North. She also sits on the Noojmawing Sookatagaing (Healing Working Together) Ontario Health Team for Thunder Bay and surrounding regions.

In 2023 she was a coordinator for the first-ever Walk for Lupus in Thunder Bay along with Lupus Ontario. Leveraging the connections she made through her role as a patient and family advisor, she curated a Northern cause after meeting with various professionals. They raised over twenty thousand dollars to train another Advanced Clinical Practitioner in Arthritic Care (ACPAC) in Thunder Bay. Throughout this journey, she has been able to share her struggles but also silver linings as a young woman living with a chronic illness. Her disease does not define her. Although it has brought much adversity, she has found healing through advocacy.





## AMANDEEP KAUR

Amandeep Kaur is the Chief Executive Officer of Punjabi Community Health Services (PCHS) in Ontario's Central Region. Under her dynamic leadership, PCHS has garnered acclaim for its culturally responsive services in mental health, addiction support, geriatric care, newcomer settlement, and social services.

With over three decades of experience in the non-profit sector, Amandeep has been a trailblazer and co-founder of the Integrated Holistic Service Delivery Model. This model, tailored to address health challenges within the South Asian community, is a testament to her deep-rooted passion and commitment. Amandeep's career trajectory reflects her commitment. Starting as a frontline staff, she progressed through continuous education, volunteerism, and collaboration with mainstream and community-based organizations. She has earned numerous awards for her work in family violence prevention and contributed to research studies.

Her resilience and commitment drive innovation, aiming to uplift community well-being. Amandeep is an inspiring advocate for change, dedicated to advancing equity and inclusivity in healthcare and social services to shape a brighter future for marginalized groups. Beyond her professional achievements, Amandeep brings personal insight as a caregiver to a child with chronic mental health challenges. Her advocacy for innovation and inclusivity is unwavering, as she eagerly anticipates further collaboration with the Council.





## DAVID BELL

David Bell and his wife Andrea are proud parents of three boys: Etienne, who died in a tragic accident in 2011 at 16 months, Emanuel, who was diagnosed as a baby with a rare genetic condition, and Florian.

His family's experiences with child health services and close ties with other families with medically fragile children prompted him to volunteer with several Ottawa-area organizations. David is a member of the family advisory committee of Roger Neilson House, a pediatric palliative care hospice. He is also a community member of the Quality and Safety Board Committee at Children's Hospital of Eastern Ontario.

David also serves as a family advisor on national research initiatives aimed at improving family caregiver mental health and centralizing reviews of ethics in research. David is a self-described Francophile — he learned French as an adult and lives in a fully bilingual household. His best French teacher is his eight-year-old son. Originally from Burk's Falls, David works in the federal public service.





## DEAN VALENTINE

Dean is a veteran of The Royal Canadian Navy. His experiences and professional competencies have been built through 25 years of service to the Canadian Forces Logistics Branch and over 14 years of volunteer community service work. His employment has been in a wide range of working environments both in Canada and internationally.

It's important to Dean to self-identify as a member of Toronto's queer community who is HIV positive, with complex medical and mental health challenges, navigating a mild to moderate cognitive impairment. Due to challenges with his diagnosis of HIV/AIDS, Dean was medically released from the Canadian Forces, finding himself challenged navigating a health care system unfamiliar to him. Successes and challenges in his personal journey have inspired his passion to become an advocate for collaborative, people-centred, holistic community healthcare.

Dean is a board member of Casey House Hospital, an active Community Advisor to the Downtown East Toronto Ontario Health Team, and a member of the Addictions & Mental Health Ontario Person with Lived and Living Experience Advisory Panel. He was the inaugural Chair of the Downtown East Toronto Ontario Health Team Community Advisory Council and co-led community engagement strategies. In addition, Dean is actively involved in community research projects with HQ Toronto (Innovative Approach to Treating Methamphetamine Use), Sinai Health (Co-Author, Culturally Appropriate Care for Diverse Older Adults Living with HIV) and has participated in various peer support programming in the area of Mental Health and Addictions and Skills for Safer Living.

*"I want to acknowledge that I come from a place of privilege and my story is unique to me. I recognize I may have similar challenges to others but our access to services may vary significantly. I want to commit to learning and assisting with breaking down barriers and oppressions that impede the provision of equitable access to healthcare. I firmly believe mental and physical health care spans over a lifetime and community healthcare should be equitable and easy to navigate, with seamless access to services, when they are needed, without delay" - Dean Valentine*



## APPENDIX COUNCIL MEMBER BIOGRAPHIES



## DON MAHLEKA

Don Mahleka was born and raised in Zimbabwe and fled to Canada as a refugee in Grade 9. He has living experience of chronic pain, trauma, depression and anxiety. He has used his experiences of facing barriers to accessing health and community services to seek insights from other people with diverse lived experiences on ways to address health care inequities.

Don is experienced in health equity consulting, anti-racism and anti-oppression training and implementation. He also has experience collaborating with equity deserving groups in program development, change management, community-based participatory research and policy development to spark innovations in health equity.

Don has experience co-hosting international, national and local mental health conferences. He co-founded Revolutionary Lives, a local youth mental health radio show that engaged and empowered youth voices from

high schools and post-secondary institutions. The radio show team hosted city-wide youth mental health conferences and advocated for a city-wide youth mental health strategy. This strategy aimed to address barriers in accessing health/social services faced by racialized youth.

Don has served as Strategic Advisor to the Chief Public Health Officer of Canada and has served on several non-profit boards. Don has also served as an advisor for the Mental Health Commission of Canada's development of two national standards: a national mental health standard for post-secondary institutions and a national standard for psychological health and safety in the workplace. He's currently supporting the development of the Commission's Structural Stigma online training module. For the Centre for Addiction and Mental Health, Don has provided advisory support for the development of an online Harm Reduction Resource and Recovery College.

Don has several years of experience in frontline peer support, mental health crisis intervention and counselling. He believes in collective impact and collective care that centres on restorative justice, cultural humility, mutual respect and accountability.



## APPENDIX COUNCIL MEMBER BIOGRAPHIES

**JOAN DUKE**

Joan lived in rural Ontario for many years before moving back to Thunder Bay and brings both rural and northern urban perspectives to her patient and family advisory lens. She became involved in-patient engagement with the Thunder Bay Regional Health Sciences Centre and moved on to develop experience on Ontario Health committees, the organization and implementation of the Noojmawing Sookatagaing Ontario Health Team, and other provincial and national health organizations. She believes that it is important to look at the individual needs of both rural and urban clients and communities.

Along with these responsibilities she brings a commitment to keep educated and up to date on health matters and patient stories and opinions. Sharing ideas in a positive and proactive way is important to the improvement of the health system.





## KAREN SAMUELS

Karen Samuels is a Child Protection worker with 23 years' experience. She holds a Bachelor of Social Work Degree from Ryerson University, currently known as Toronto Metropolitan University.

She works with children, youth, and families of various cultural, social, and complex needs who have experienced trauma throughout their lives. She is well versed in the areas of addictions, mental health, homelessness, emotional intelligence, human trafficking, immigration, and kinship services. Her current role involves engaging and collaborating with various departments within the Peel Children's Aid Society to support with service gaps. Additionally, she collaborates with various sectors including children's mental health, school boards, adult mental health and addictions, families in transition, court and medical.

During her career, she has had a range of opportunities and experiences, the first of which is mentoring interns and workers with a focus on diversity, equity and inclusion. She has been a member of the Peer Support team which offers support to fellow colleagues. She has also collaborated with community partners both independently and in her role as supervisor of the adolescents' team, The Associated Youth Services of Peel and Everymind Mental Health Services.

Karen has experienced many trials and tribulations as a black woman seeking health care support for herself, family & clients. Karen is a cancer survivor and dealt with the complications of COVID-19. Karen is a caregiver to elderly parents with complex health issues.



## APPENDIX COUNCIL MEMBER BIOGRAPHIES

**SANDI BELL**

Sandi Bell is the President of EMPOWORD Inc., a mediation and training & development firm. She has an extensive background dealing with interpersonal and organizational conflict, strategic planning, change management, human rights, social justice, anti-racism and anti-oppression, child welfare, education, youth matters, accessibility, disability issues and equity/diversity/access/inclusion.

Ms. Bell is currently a part-time Commissioner of the Ontario Human Rights Commission (OHRC). Throughout her terms as a Canadian Human Rights Commissioner (CHRC), Sandi has been proud to engage in various levels of the National Aboriginal Initiative. This is a multi-faceted set of strategies to help members of the Aboriginal community to use their rights under the CHRC.

Sandi has advocated for and provided extensive consultation services and training around Ontario's disability legislation and standards, as well as the Ontario Human Rights Code. She has been a coach with the Windsor Law School Mediation Program and a guest lecturer with many educational facilities, including Osgoode Hall Law School. Sandi taught a business program at Mohawk College and taught Community Development at Ryerson University's Disability Studies Faculty.

She proudly self-identifies as a Black Indigenous woman with a disability. Her passion to rid society of — and prevent — racism, discrimination and oppression is not a topic or research project — it is a way of life.





## SANDRA HOLDSWORTH

Sandra Holdsworth is retired from a 30-year career in the banking industry where she held various positions in administration, finance, facilities and retail banking. She received a liver transplant 27 years ago, after going undiagnosed with a rare liver disease, Primary Sclerosing Cholangitis and Crohn's. After years of treatment for her Crohn's, she required a permanent Ileostomy in 2012. Sandra currently has chronic kidney disease.

Using her lived experience as a transplant patient and a benefactor of organ donation, she is an advocate for organ and tissue donation, while also mentoring others waiting for and recovering from a transplant. Sandra is very interested in the health care system as a whole and how we can improve it with co-design, including patients in system transformation, patient safety, research, and more. Sandra is in favour of including patients and their caregivers as active partners in their health care and treatment plan.

For over a decade, Sandra has collaborated with the Canadian Donation Transplant Research Program as a patient partner co-lead on the Quality-of-Life Theme. She helps to determine and design research projects,

and recruit and assist with knowledge translation. She is involved in several research projects including exercise, nutrition and mental health, Patient Reported Outcome Measures (PROMs) & Patient Experience Measures (PREMs), AI & machine learning, patient engagement Evaluation, and so many more.

Sandra joined the Muskoka and Area Ontario Health Team in July 2019, serving on the Steering Committee and Alliance Council as well as several working groups and task forces. Along with her co-chair, she participated in the application submission and co-led the development and leadership of the Muskoka and Area OHT Patient Family Caregiver Partner Advisory Committee. Sandra stepped down from this role in December 2023 to focus on provincial engagement. Recently, she has represented the Minister's PFAC on the OHT System Transformation Advisory Committee and the OHT Performance Measures Working Group.

Sandra joined the Ontario SPOR Support Unit Patient Partners Working Group in 2022. Sandra is on the Board of PAN (Patient Advisors Network). Locally she volunteers with Gravenhurst Against Poverty assisting with their communications. Sandra is also a co-chair of Ignite Gravenhurst.





## SHANNON MCGAVIN

Shannon McGavin (she/her) is a system change leader dedicated to creating people-centred teams and facilitating community partnerships. Driven by a commitment to integrated care, diversity, inclusion, psychological safety, and the importance of including lived and living expertise, Shannon focuses on co-creating transformative change to improve youth and community wellness in rural communities across Canada. Having worked for more than 25 years to enhance outcomes in education for children, youth and their families, Shannon believes that working together with local, national and international contexts is instrumental in creating shared purpose and evidence-based integrated care.

As a parent of young adults who have struggled with anxiety, depression and eating disorders, Shannon has experienced first-hand frustration with the lack of sustainable and supportive systems for youth struggling with mental wellness. As the CEO and Founder of The

Well Community Collective, she is transforming youth wellness pathways to support youth in rural Huron, Perth, Grey and Bruce Counties with Integrated Youth Service Networks.

Most recently, Shannon has used her lived expertise as a cancer survivor to continue advocating for transparent patient navigation, integrated care systems, and safe, welcoming care spaces and providers.

Currently, Shannon is a member of the Family Advisory Council at the Knowledge Institute of Child and Youth Mental Health and Addictions, and she supports several Knowledge Institute CIHR projects and Co-Chairs the Quality Standards Advisory Council. She is a member of her local Huron Perth and Area Ontario Health Team, sitting at the Patient Family Caregiver, Mental Health and Addictions Network and Planning and Priority setting tables. Shannon is a life-long learner who is finishing her Master of Youth Mental Health degree at Orygen in Australia.





## SHEQUITA THOMPSON-REID

Shequita Thompson-Reid has been working at the intersections of community development and equity for over 15 years. She offers expertise within the fields of program development, youth engagement, capacity building, housing, violence prevention, conflict mediation and equity. She is well versed in working from practices rooted in decolonization and anti-oppression frameworks.

Shequita is the Founder & Principal Lead of STR Consulting. She has developed, led, and facilitated training and education on topics such as conflict mediation, violence prevention, equity, and anti-oppression. She has extensive knowledge working with youth, Indigenous, LGBTQQIP2AA, VAW and racialized communities. Shequita has extensive experience with adult and youth development and education and excels at working from an anti-oppression/anti-racism framework and challenging anti-Black racism. She holds an Honors Bachelor

of Arts from the University of Toronto with a specialization in Sociology and Gender Studies.

Shequita also co-founded a grassroots program, Words of Wisdom. This program used books as a catalyst towards having deeper conversations about inter-generational trauma, identity, equity and healthy relationships. In 2015, she travelled to Ghana to participate in a knowledge exchange with young women and girls globally, and developed collaborative strategies to end gender-based violence.

She has lived experience both as a patient and family/caregiver supporting family members navigating mental health, dementia and ADHD. Her role now extends even further as a mother of two, with her own experience related to health and the birthing journey as it relates to health equity and justice.





## WENDY DE SOUZA

Wendy De Souza is a cis Latinx woman, first-generation Canadian with Indigenous ancestry in Brazil. With over nine years as an experienced public educator, prolific public speaker and community mobilizer, she is driven by her passion for community development and facilitating transformative spaces through decolonizing pedagogies. With a background in real estate, project management and popular education, her work is rooted in decolonizing institutional spaces and practices by working from an intersectional feminist lens and an anti-colonial/anti-oppression framework. In her intergenerational and cross-sectoral collaborations, she has been recognized for her extraordinary commitment to using arts-based practices to foster individual transformation and systems change.

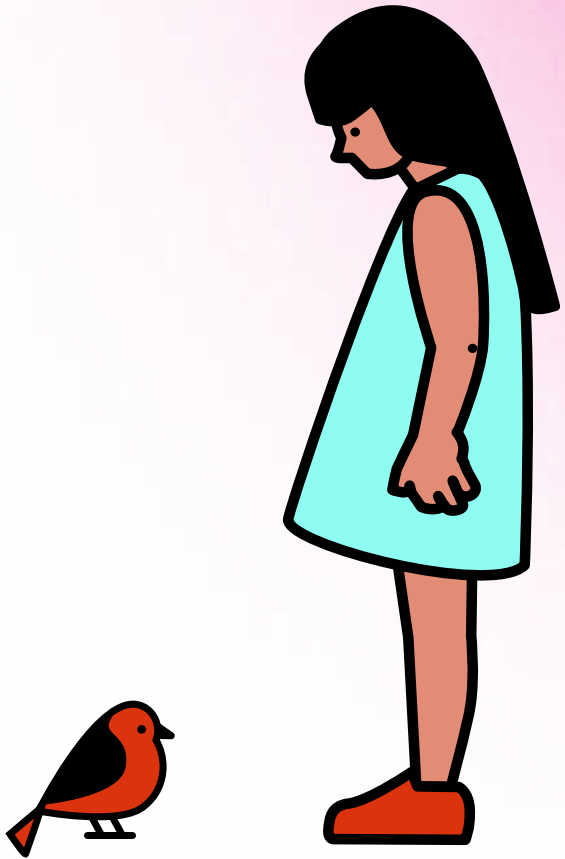
Wendy has served as a community educator, project manager and program developer. She has almost 10 years of direct community engagement experience designing and delivering high-impact community

projects, trainings, consultations and educational initiatives. She has also worked at the intersections of gender-based violence and violence against women. Wendy has spearheaded projects that engage vulnerable and marginalized African/Caribbean/Black, 2SLGBTQIA+, Muslim, racialized and newcomer communities in violence prevention and community economic development initiatives advancing the social determinants of health. She has supported the development of accessible youth legal resources on cyber violence and human trafficking, community-based research and action initiatives for Two Spirit, nonbinary and trans communities, and training resources for senior leaders in organizational equity.

Wendy has lived and family experience navigating complex birth issues, mental health, ADHD, PTSD and chronic pain. She has also supported others through health care issues like abortion and birth control, gender reassignment/affirmation surgery, addictions and health equity.



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