2022-23

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

Embracing Change: Shifting Mindsets, Changing Culture

The Collective Impact of Patient, Family, and Caregiver Partnership and Engagement

Ontario

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Land Acknowledgment

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 people from Nations from across Turtle Island.

Long before today, Indigenous people 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-Spirited 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.

Chair’s Personal Reflection on Reconciliation

As part of my own journey of reconciliation as Chair, I would like to take the opportunity to recognize my privilege as a white settler and my role in reconciliation. My ancestors arrived from Scotland and settled in Toronto. I currently live in Georgetown, which is located on the treaty lands and territory of the Mississaugas of the Credit First Nation and the traditional territories of the Haudenosaunee and the Huron-Wendat.

My fear of making a mistake in my personal reflection has held me back in the past. I am now leaning into my discomfort and recognizing that as a leader, it is my responsibility to be honest and authentic. I also want to acknowledge that many of my ancestors who settled in Toronto were high ranking Salvationists, and several ran an institution for justice system-involved youth with mental health and substance use issues. I recognize the impact and trauma that has been born from religious structures aiming “to save people”. I recognize the impact and trauma that religious and colonial institutions have caused.

I acknowledge that colonial violence continues to negatively impact Indigenous peoples. I will be conscious of these colonial harms and continue to learn about our past, while supporting engagement and partnership with Indigenous people towards reconciliation. As I learn and grow in my relationship to this land and its Indigenous people, and by unlearning colonial practices, I hope to lead by example.

-Betty-Lou Kristy, Chair of the Minister’s Patient and Family Advisory Council

Message From Sylvia Jones, Deputy Premier and Minister of Health

I am very pleased to accept the Annual Report of the Minister's Patient and Family Advisory Council for 2022-23. It has been an honour to engage and partner with the Council, and this report is critical to building a health system that is rooted in patient-centred care.

As outlined in Your Health: A Plan for Connected and Convenient Care, our government is improving all aspects of health care in Ontario and putting people at its heart. This includes a bold vision for advancing patient-centred care by delivering health care services closer to home and making it easier for patients and families to connect to the care they need. We are focused on better health outcomes and the patient experience for Ontarians, making it easier to navigate care at every stage of life.

Our work to better connect and coordinate care for Ontarians includes the expansion of Ontario Health Teams across the province. The Council has been a core partner in informing guidance and supports provided to Ontario Health Teams, including the November 2022 Path Forward document.

Throughout this past year, the Council has been a strong partner in providing advice on key health care topics, from accessing personal health information to ensuring that health care services are available within the community. The Council has also been instrumental in developing a plan to implement the Ontario Health Data Council recommendations for addressing barriers to the sharing of information, including with patients, families and caregivers, to be partners in their care.

I want to take this opportunity to again extend my deepest thanks to the Council's Chair, Betty-Lou Kristy for her partnership and tireless advocacy. Her leadership has fostered a nurturing and collaborative environment that honours the crucial role that patient, family and caregiver advisors play in organizations across the province.

To the members of the Council, I offer my gratitude and appreciation. A tremendous thank you to Amandeep Kaur, Dean Valentine, David Bell, Don Mahleka, Joan Duke, Kimberly Cato, Sandi Bell, Sandra Holdsworth, Shannon McGavin, Shequita Thompson-Reid, Sterling Renzoni and Wendy De Souza.

It is a privilege to engage with you on many of the pressing issues impacting patients in Ontario. You have contributed significantly to our health care system, and I look forward to continuing and strengthening our partnership.

Stay well.

Sylvia Jones
Deputy Premier and Minister of Health

Message from Betty-Lou Kristy, Chair of the Minister's Patient and Family Advisory Council

Wow – what a year! It feels like our pace has accelerated to warp speed. Yet ultimately, change still feels too slow. As we continue to recover from the pandemic, important changes to the health system are underway. These forces have further surfaced the health disparities and inequities for people who face barriers within the system. These barriers can have a significant impact on how people access and experience their care and, as a result, underscore the importance of embracing meaningful change.

This brings me to the main theme for this year's Minister's Patient and Family Advisory Council Annual Report: Culture Change. There are tangible results and important collective impacts when true partnership, engagement, and co-design takes place with patients, families, and caregivers. It's an ongoing journey, but we are on the right path.

This year, the Council has embraced culture change by sharpening our focus on diversity, equity, anti-racism, accessibility, and reconciliation. Socially competent care, the broader social determinants of health, and effective population health management are foundational cornerstones needed to transform the health care system and have been key areas that have grounded the Council's advice.

As the Chair of the Council, my hope for change includes a more humanized system that meets people where they are, providing the services that they want and need. I truly believe that this change in mindset leads us to the intersection of curiosity, possibility, and enormous advances in health care. We truly need to lift each other up. We can grow enormously by stepping out of bias, judgment, stigma, and discrimination. Reaching out to others who may be struggling can mean more than we know. We can share knowledge, sentiment, and grow stronger together. We are all emerging leaders in our own way, if encouraged and given a chance to shine our light.

Being the Chair of the Council has been so meaningful to me. I'd like to thank the Honourable Sylvia Jones, Deputy Premier and Minister of Health, for her support, trust and time. I would also like to express my appreciation and thanks 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, bravery, and determination.

Through the contributions of the Council, those with lived/living experience, patients, families, and caregivers have helped shape health care transformation in Ontario. Our lived experience is fueling the cultural change from “storytelling” to evidence. We are providing a road map to affirmative change.

Betty-Lou Kristy
Chair, Minister's Patient and Family Advisory Council

Thank you to my team

I want to thank the team at the Ministry of Health, which supports me as Chair and the Council as a whole. 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 team. They are my biggest supporters in so many ways. Allison, Jessica, Michelle, Chris, Madi (and Kevin and Nikita who have moved on) 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.

Betty-Lou Kristy

What is allyship?

Allyship is active support for the rights of an equity-deserving group. It involves upholding safe spaces where experiences and voices are heard and understood. Allyship includes understanding and articulating our own positioning, and actively participating in the removal of barriers so all people can feel safe and enabled to actively participate. It also includes uplifting the work already in progress by those we are in allyship with, and honouring the existing spaces for these voices and groups.

With thanks for contributions from Alyssa Gremmen, Peer Integration and Systems Lead, Support House Centre for Innovation in Peer Support.

Inclusive language

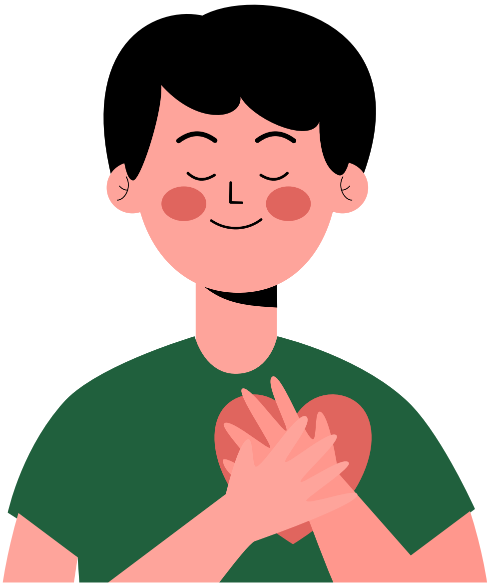
In this report, the term "patient" is inclusive of those who identify as a client, citizen, resident, community member, those with lived/living experience and any others who may interact within the health care system. The term family and/or caregiver is inclusive of people who are providing support and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

Personal Narrative: Stigmatized and irrevocably harmed - a mother, her late son, and the impact of stigma

Let's be clear: stigma is judgement, bias, and discrimination. One of the most effective ways to champion change is by humanizing, sharing our personal journeys, and fostering a compassionate culture. We can co-create brave spaces and demonstrate our allyship. If we truly care about learning and improvement, it is our collective responsibility to do the work. This means speaking honestly about the barriers, unmet needs, and harms that have been caused by stigma and discrimination at social, cultural, and health care system levels.

Both my late son and I struggled with substance use and mental health issues. Pete and I had a unique and beautiful relationship. We still do. His sense of humour and general "weirdness" truly entertained me. We found great solace from our struggles and lots of laughter, despite all the challenges. Pete was definitely a character. His knowledge was incredible. Even when it did not make sense to me, I recognized that it made sense to him. What I assumed might be nonsensical was actually an authentic worldview that included the universe, the arts, and literary works such as Alice in Wonderland. He was my upside-down kid. But now I understand the wonderful perspective that he had.

Pete died on December 23, 2001. He was 25. He died from an accidental mixed drug overdose while on a psychiatric hold in the hospital. At least that is how he technically died, but I know he died from loss of hope and feeling like the world did not care about him. That he was an "addict". That it was his fault. No matter what I did, I could not love my son back to wellness or restore his dignity. In large part, because I did not have any self-worth myself. That had been stripped from me too. An indelible stain that was left over from when I too was considered a useless "addict".



The most prevalent labels we received from the professional world and society were “alcoholic” and “drug addict”. Those labels caused us to be condemned. Somehow those labels denigrated our true needs and stripped our value as human beings. It was judged that our complex mental health issues basically came from our “lifestyle choice” to use substances. In short, we were blamed. Just imagine how that felt.

For both my late son and I, the most pervasive and damaging harm was the way we were treated. Society dismissed us. Care providers did not want us. Our little family was fighting for survival. We were stuck in a tornado. Pete didn’t survive.

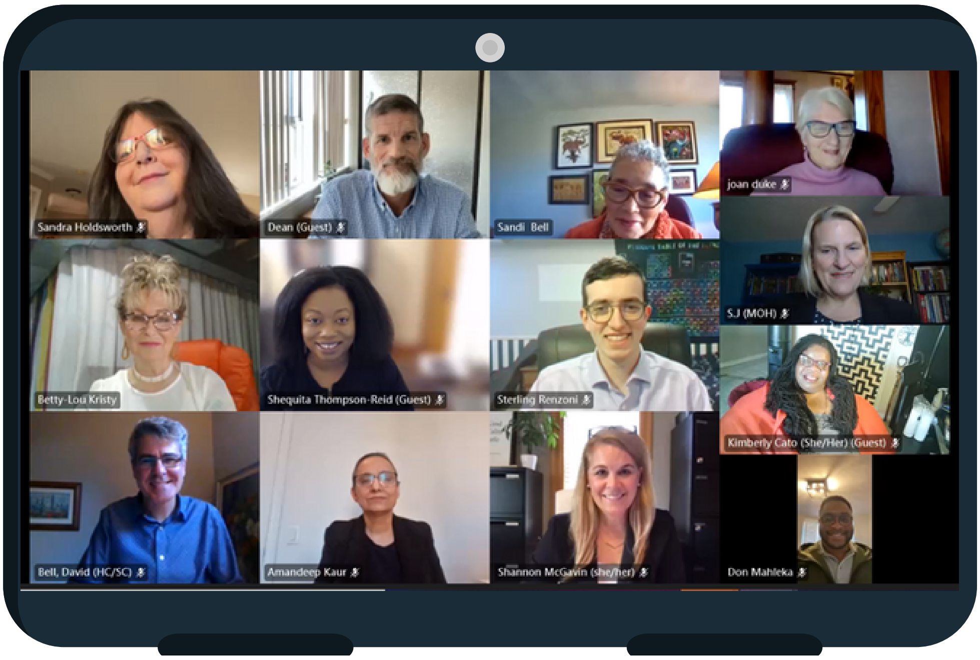
Pete and I were both impacted by so many layers of stigma at so many intersections of our collective journeys. Stigma contributes to the destruction of life. It is a barrier to care and is culpable in many deaths. It is inherently dangerous to any vulnerable person because it has this innate ability to de-humanize us.

As a person with this lived experience – someone who received care but very little actual caring, and as a bereaved mother who watched her haunted son turn into a ghost that nobody seemed to care about – culture change is about the foundational layer of truly caring about each other.

Together we can embrace change, shift mindsets, and celebrate each other.

-Betty-Lou Kristy

Overview of the Minister's Patient and Family Advisory Council



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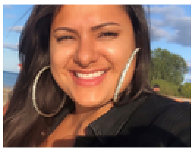


Wendy De Souza

Minister’s Patient and Family Advisory Council Chair and members with Sylvia Jones, Deputy Premier and Minister of Health, October 2022.

The Council is a provincial advisory body to the Minister and Ministry of Health (‘ministry’) with a mandate to help improve patient care by ensuring that the voices of patients, families, and caregivers are at the centre of policy development and decision-making. The Council is made up of 12 members, plus the Chair. The Council is a diverse, thoughtful, and professional group invested in providing expert advice on health system transformation priorities.

Council priority areas for 2022-23

The Council Chair and the Minister of Health work together to identify priority areas of focus for the Council. The Council then provides insight and advice on emerging health system priorities, at the request of Minister and ministry.

The priority areas of focus in 2022/23 were:

- Digital Health and Virtual Care
- Ontario Health Teams
- Home and Community Care
- Mental Health and Addictions

Council's focus, expertise and passion

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

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

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, Harm Reduction, Community Building, Peer Support, Engagement, Governance, Human Resources, Research, LGBTQ2I Advocacy

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, Chronic Conditions, Advisory and Empowerment, Community Engagement, Virtual Care, Digital Health, Policy Review, Quality Control, Research

Council's focus, expertise and passion

Kimberly Cato: Former Ordained Minister and Chaplain, Vision/Hearing and Mobility, Trauma, Mental Health, Body Image Issues, Life Altering Chronic Pain, Equity, Anti-Racism, Children in Care, Youth, Seniors, Palliative Care, Justice

Sandi Bell: Black Indigenous woman with disabilities, Human Rights, Social Justice, Anti-Racism, Anti-Oppression, Mental Health, Child Welfare, Accessibility, Disability Issues, Equity, Diversity, Access, Inclusion, Mediation, Training

Sandra Holdsworth: Transplant Recipient, Organ and Tissue Donation, Chronic Disease, Mental Health, Social Determinants of Health, Research, Co-Design, Knowledge Translation, Engagement, Leadership, Patient Partnership, Quality Improvement, Training

Shannon McGavin: Over 25 Years in Education Field, Rural Communities, Youth and Community Wellness, Mental Health, Substance Use, System Change, People-Centred Teams, Transformative Change, Research, Health Standards

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

Sterling Renzoni: Mental Health, Trauma, Eating Disorders, Child Pediatrics, Transitional Age Youth, Schooling in Hospitals, Transitioning to Community, Social and Academic Stress, Youth Facilitator, University Outreach, Speaker

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

Supporting culture change within the Council

What do we mean by culture change?

Co-designing and co-producing health care programs and policies with patients, families, caregivers, and those with lived/living experience can lead to culture change. Examples of demonstrating culture change can include when patient, family, and caregiver partners are valued and supported, and when the importance of partnership is appreciated and recognized by individuals, organizations, and within the health system.

"As a leader in community engagement and education, my passion lies in creating a truly inclusive space for equity-deserving communities. Through my work with newcomers, Black, Indigenous, 2SLGBTQIA+ and racialized youth, and mental health advocates, I bring a unique perspective to the Minister's Patient and Family Advisory Council that is grounded in a deep understanding of the unique challenges and barriers these communities face.

I understand that it is not enough to simply acknowledge these challenges – we must actively work to dismantle the systemic structures that perpetuate them. To achieve this, we must prioritize an equitable, anti-racist, inclusive and accessible lens when shaping our patient, family, and caregiver partnerships. We must recognize and address the power imbalances that exist within the health care system and actively work to shift the centre of care to the perspectives and experiences of those who have been historically marginalized. Only then can we create a true culture change that centres around the needs of our most vulnerable communities. Taking this approach can be hard work, but it is also "heart work," and it requires us to stretch ourselves to listen, to have empathy and intentionally do the work to integrate the voices of those who have been most harmed by our systems, so that we can collaboratively repair and rebuild the future of health care.

Ontario continues to model the ways we can do this 'heart work' through engagement practices and co-creating an equity-centered culture shift that values the voices of all. I am committed to working with my fellow Council members towards a health care system that is truly inclusive, accessible, and affirming for all."

Wendy De Souza, Council member

By the numbers

Anonymous feedback from Council Members about their experience on the Council:

- 89% agreed or strongly agreed that they are able to express their views freely during Council discussions, that their views are heard.
- 75% agreed or strongly agreed that Council members represent a broad range of perspectives.

442 hours of direct engagement with the Council, representing 17 unique engagement sessions

Council Chair time spent partnering and co-designing with the ministry and ministry partners:

- Over 180 hours of system partner engagements
- 24 hours interacting with Ontario Health Teams (OHTs)
- 18 hours of other speaking engagements, representing nine unique engagements

Seven virtual visits by the Council Chair to assess the patient, family, and caregiver engagement capacity in developing OHTs:

- Maamwesying OHT
- City and District of Thunder Bay OHT
- Kiiwetinoong Healing Waters OHT
- Four potential teams from Northeastern Ontario (in review)

More than 1,400 patient, family, and caregiver advisors in the ministry's virtual pool of patient, family, and caregiver advisors

Moving Towards Culture Change

The Council plays an important role in creating more patient-centred health care in Ontario. As a permanent provincial advisory agency, the Council is an important contributor to how health care policy is developed and implemented in Ontario.

Changing culture happens over time and is grounded in changes in attitudes and behaviours at multiple levels of health care delivery and planning. At times, it can be difficult. As members of local OHTs and as community leaders, Council members also work with local providers and as peer leaders with other patients, families, and caregivers.

Throughout 2022-23, the Council has worked with OHTs, the ministry, Ontario Health, and leading researchers to actively support an integrated and patient-centred health care system.

Next, the report focuses on four areas where the Council has advanced culture change so that patient, family and caregiver:

1 - Partners and their contributions are valued
2 - Perspectives bring greater understanding and appreciation
3 - Engagement and partnering is sustained beyond the support of an organizational champion
4 - Partners are embedded advisors

1 - Patient, family, and caregiver partners and their contributions are valued

Reflections on Council engagements with the ministry

Cultivating a safe environment for genuine partnership is critical to the successful collaboration of the Council. The Council has implemented processes and resources, including a code of conduct and self-care practices, as part of its regular operations. Council members have a wealth of experience engaging but recognize that discussions can still be triggering. The Council knows that effective partnership requires a trauma-informed approach from all those participating, including the Council members, Chair, and the ministry.

As the ministry engages with the Council, they validate advice received in meetings through written summaries and take care to provide members with multiple opportunities to provide input. These feedback loops are an important way to demonstrate that the valuable advice of the Council has been captured as intended and to provide a report back on progress.

In Fall 2022, the Council completed a survey related to their engagement with the ministry. Key feedback from Council members highlighted that:

- 93% felt that a safe, inclusive, and trauma-informed space is established for meetings and engagements
- 91% felt that their views are heard and respected
- 88% of members felt that the Council is achieving its mandate
- 86% of members expressed that they feel that the work of the Council makes a difference to the ministry

The Council also identified opportunities for growth and improvement, particularly in how they feel that their work is influencing ministry policy and program implementation.

2 - Patient, family and caregiver perspectives bring greater understanding and appreciation

Digital health and virtual care

> “The ministry is grateful for the hard work of the Council, and we value the time we spend engaging with them. The conversations and insights continue to be a catalyst to advance the digital health strategy in ways that resonate with all Ontarians.”
>
> **Michael Hillmer, Assistant Deputy Minister, Digital and Analytics Strategy Division**

Over the last year, the Council provided advice to support improvements to the provincial digital health strategy. Engaging with the Council on a routine basis has enabled active contribution from the earliest stages of program and policy development through to implementation. For example, the Council provided early input on the priorities identified for the Unified Patient Experience, which aims to create seamless digital health experience for all Ontarians.

The Council also informed the initial requirements for the Health811 digital service prior to its launch in Spring 2022. They play an ongoing role in helping to evolve and improve the service through participation in both the Health811 Stakeholder Advisory Council and annual roadmap engagement sessions.

The Council has also been a close partner in the development of the ministry’s policies to improve digital access to personal health information. Understanding what the Council identifies as important to patients, families and caregivers has had a significant influence on digital health and data policy decisions.

In November 2022, the Ontario Health Data Council released their report A Vision for Ontario's Health Data Ecosystem. The Council were engaged on the recommendations of this report and are partnering with the ministry to consider how the vision of the report can be implemented. They have outlined the importance of data transparency, building public trust, improving data literacy, and opportunities for Ontarians to provide advice on provincial health data and privacy policy.

In January 2023, the Ontario Health Data Council and Minister's Patient and Family Advisory Council launched a working group chaired by Betty-Lou Kristy and composed of Council members.

> "The Ontario Health Data Council has benefitted from the valuable perspectives and advice of the Minister's Patient and Family Advisory Council. We will continue to partner to ensure the lived experiences and interests of Ontarians are represented in the work ahead."
>
> **Dr. Jane Philpott, Chair of the Ontario Health Data Council**

This working group's goal is to advise on a civic engagement approach for health data in Ontario. Council members have expressed the need for data to be used and represented in an equitable and trauma-informed way, for the good of all.

Through working group sessions, the Council indicated that equitable access to personal health information by patients, families, caregivers, and providers is a foundational component of care quality and patient safety. Members have given advice on actively considering the impact of harms experienced by equity-deserving groups, including Black and Indigenous communities, related to the use of data. In addition, the Council has emphasized the importance of comprehensive privacy protections and safeguards for individuals, groups, and communities.

Home and community care

The Council has engaged with the ministry on the implementation of a plan for home and community care modernization including new home and community care regulations under the Connecting Care Act, 2019. These regulations are intended to support more connected, easier to navigate, higher quality, and patient-centred delivery of home and community care services for patients, families and caregivers.

> “Working with the Minister’s Patient and Family Advisory Council provides the Home and Community Care Branch of the Ministry of Health with valuable and practical insights, and also re-inspires us and deepens our commitment to keeping patients and their families at the front of our minds in all the work we do. In particular, the Council’s advice and inspiration has helped the ministry with home and community care modernization, including in 2022 to update, strengthen, and expand the legislative framework for home and community care. The Council’s perspectives have helped the ministry advance initiatives to modernize home care delivery and the role of care coordination. Engaging with the Council is always a productive, enlightening, and meaningful experience, and we greatly appreciate members’ contributions to home and community care policy development and implementation.”
>
> **Amy Olmstead, Director, Home and Community Care Branch**

Building on the advice of the Council, the regulations support the involvement of patients, families, and caregivers in the delivery and planning of their care. This includes:

- establishing the right for patients (and their designates) to receive information about their care in a manner that is clear and accessible to them,
- outlining requirements for investigating patient care complaints, and
- sharing information across providers to improve transitions in care and the patient experience.

The Council has also provided advice on the importance of:

- ensuring a stable health care workforce and robust care coordination supports for families
- improving the self-directed home care program to address administrative barriers
- determining the appropriate role of virtual care
- ensuring culturally appropriate care across populations
- measuring impacts on equity of access as home care is integrated through OHTs

Mental health and addictions

> “The Mental Health and Addictions Division is grateful to the Minister’s Patient and Family Council for ensuring that clients and families remain at the centre of our work to build a world class mental health and addictions system and invest in innovative programs like Youth Wellness Hubs Ontario.”
>
> **Kyle MacIntyre, Assistant Deputy Minister, Mental Health and Addictions Division**

The Council provided strategic advice on the expansion of Youth Wellness Hubs Ontario’s (YWHO) integrated youth services program. Youth Wellness Hubs provide care for youth substance use, concurrent disorders, and transition-aged youth by providing walk-in access to primary care, addictions, and mental health services for people aged 12 to 25. These services are paired with a range of other services and supports in the fields of education, employment, training, housing and other community and social services.

The Council's advice centred on the opportunity to strengthen engagement efforts directly with youth accessing Youth Wellness Hubs. The Council emphasized the need to consider tools and supports, such as specialized community outreach to connect with equity-deserving and underserved populations and establishing transportation solutions to make services more accessible to youth, especially in rural areas. The team at the YWHO Provincial Office are working to embed the Council's advice into operational planning.

Independent Health Facilities / Integrated Community Health Services Centres

The Council was engaged on the ministry's plan to implement community and surgical diagnostic centres to support care delivery in local communities.

The Council identified that priorities for patients, families, and caregivers include sustainability and the longer-term costs of expanding the community and surgical diagnostic program. They noted that there is a need to ensure patient, family, and caregiver perspectives are included as implementation continues. The Council advised that community and surgical diagnostic centres should be guided by core values grounded in the Patient, Family, and Caregiver Declaration of Values for Ontario. Public education and promoting public awareness about these community-based medical procedures were also highlighted.

The Council also advised that the provision of culturally safe care and equitable patient access to care in these settings are critical to successful implementation.

3 - Patient, family and caregiver engagement and partnering is sustained beyond the support of an organizational champion

Ontario Health Teams

In November 2022, the ministry released new guidance for OHTs in The Path Forward. The Council provided critical advice to shape this guidance.

The Council emphasized that OHT implementation should continue to be grounded in a vision of integrated care and population health management. For example, the Council advised that as OHTs implement integrated clinical pathways, a comprehensive approach to caring for the whole health of a patient – including their comorbidities and social determinants of health – is needed. The Council also recommended that OHT corporate structures require strong patient, family, and caregiver representation to support authentic co-design and partnership. The Council also recognized that there is an opportunity to improve public awareness of OHTs.

The Council's advice has informed policies, resources, and other supports for OHTs. The Council Chair and the ministry partnered with the Rapid-Improvement Support Exchange (RISE) to develop a dedicated hub of patient, family, and caregiver engagement and partnership resources. This hub provides easy access to practical resources, tools, and training.

> "OHTs have true champions in the Minister's Patient and Family Advisory Council. The ministry and Ontario Health have benefited immeasurably from the on-the-ground perspectives of OHT patient, family, and caregiver leaders as we as develop policies and programs. These partners are committed to the success of OHTs and routinely provide advice on all aspects of the OHT model, with a special focus on ensuring OHTs truly embed meaningful co-design in all they do. It is a true pleasure to work alongside Council members to enhance OHT implementation."
>
> **Allison Costello, Director, OHT Policy and Operations Branch**

"My participation with the Council has been an inspirational journey with opportunity for capacity building for myself and my regional community. I have seen my ideas, feedback and lived experience valued.

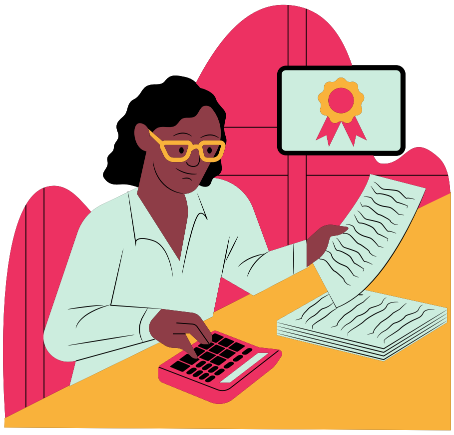
I feel proud to be an equitable team member of the collaborative efforts of the ministry, Ontario Health, and community members to guide Ontario into a community health care model where the patient, family, and caregiver voice is at the forefront of its decisions and part of leadership."

Dean Valentine, Council member

"Contributing lived/living experience into health care as a part of the Minister's Patient and Family Advisory Council means adding my voice to the passionate and diverse voices of my fellow Council members. This includes the initial identification of issues all the way to the implementation and dissemination of policy. As someone with lived experience of mental illness, the work we do on the Council is meaningful to me as it provides a means to create needed change within the health care system. Additionally, the Council can serve as a source of inspiration for those battling mental or physical illness, that there is a light at the end of the tunnel, and they can go on to do great things!"

Sterling Renzoni, Council member

Supporting continuous improvement

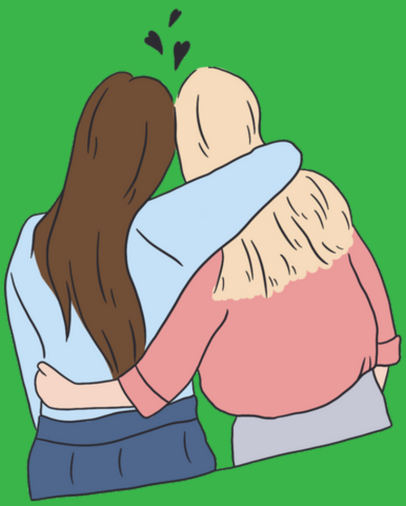


The Council partnered with the Public and Patient Engagement Collaborative to conduct a self-assessment and review of Council engagements with the ministry. The Council leveraged cutting edge tools, including the Public and Patient Engagement Evaluation Tool and the Engage with Impact Toolkit, to support this self-assessment.

Results have informed recruitment practices for the Council, feedback mechanisms, and improvements to supports for Council members and program areas within the ministry to enable effective partnership and engagement. Excerpts of the self-assessment results are found throughout this report.

"The Minister's Patient and Family Advisory Council's leadership in evolving and instituting ideas on co-design, and their promotion of understanding of inclusion, equity, and equality for health organizations, has given me the confidence to know that I can move forward positively. Working with my fellow Council members inspires in me an authentic, informed passion to promote effective, positive, and inclusive change."

Joan Duke, Council member



4 - Patient, family, caregiver partners are embedded advisors

As Council Chair, Betty-Lou Kristy plays an integral role as a leader and steward for patient, family, and caregiver engagement and partnership in Ontario. Betty-Lou's strategic advice spans the Council's priority areas and beyond, as she is a key partner in many health transformation initiatives. Betty-Lou is committed to transforming the health care system to provide more humanized, holistic, and integrated care.

Speaking engagements

- Healthy Workplace, Healthy Mind keynote: Ontario Public Service event focused on increasing awareness of mental health and substance use/addiction.
- Mental Health Secretariat keynote: Multi-ministry executive table on the coordination and delivery of mental health and addictions services in Ontario.
- Provincial Webinar keynote and other engagements with OHTs: Remarks to the province on The Path Forward guidance in November 2022. Keynote addresses with several individual OHTs on partnership and co-design, trauma-informed engagement, and the work of the Council.

Strategic advice

- Member of the Health811 Executive Steering Committee: Representing patient, family, and caregiver perspectives to support the planning, implementation, and optimization of the provincial health navigation service known as Health811.
- Member of the Ontario Health Data Council and Chair, Civic Engagement Working Group: Championing the role of patients, families, and caregivers in informing how health data should be collected, shared, and used for the public good. Chairing a working group co-sponsored by the Ontario Health Data Council and composed of Minister's Patient and Family Advisory Council members.
- Co-Chair, Working Group for Creating Engagement Capable Environments in Ontario Health Teams: A Framework for Action. and OHT Patient, Family, and Caregiver Community Engagement Series: Involvement in time-limited working groups composed of patient, family, and caregiver partners, researchers, OHT leaders, and the ministry to support OHT development.

"As a Black woman who engages with the world from a wheelchair, I am acutely aware of how much my intersectional identity renders me vulnerable to potential harm in a health care system that does not centre health equity or the empowered patient, to ensure that our autonomy is maintained. Collaboratively working on the Minister's Patient and Family Advisory Council to co-design the new health care system demonstrates an awareness that the end user is the expert in developing their care."

Kimberly Cato, Council member'

"I enjoy being a member of the Minister's Patient and Family Advisory Council and being provided with a platform to provide input and suggestions into the framework of our health care system. I feel fortunate to be able to share my perspective on programs, services, and processes to make the health care experience better for all.

With my many years of lived experience with a liver transplant, Crohn's Disease, a permanent ileostomy, and chronic kidney disease, I have journeyed throughout our health care system. I have gained knowledge that gives me an ability to see what is working and not working. I can provide a perspective on ways to create a more integrated health care system resulting in better health outcomes.

Being Co-Chair of the Muskoka and Area OHT Patient Family and Care Partner Advisory Council, as well as a member of the planning committee for the OHT Community of Practice, provides me with a better understanding of our health care system and how integrated care, collaboration, and co-design can improve the patient, family, and caregiver experience. By being engaged at these various levels I have learned what is important to patients, families, and caregivers and can express these concerns or ideas at our Council meetings.

Having more patients, families, and caregivers as equal partners in the transformation and co-design of our health care system is a culture change which takes time and trust. We are moving in that direction.

By collaborating together, we will create a health care system that achieves the objectives of the Quadruple Aim , improved patient and caregiver experience, improved patient and population health outcomes and improved provider work-life experience."

Sandra Holdsworth, Council member

Embracing Change: Closing remarks from the Chair

Culture change – real culture change – needs champions at all levels. As Chair, I have had the privilege of being a partner in the work of lived/living experience and patient, family, and caregiver engagement for many years. I continue to be humbled and inspired by my colleagues. It can be a long and arduous journey to move boulders (i.e. system barriers) and convince society that we all need to be valued and equitably supported to participate in engagement, partnership, and co-design.

That being said, I have seen profound and exciting change happen. Are the changes enough? No. Not even close. But with the benefit of longevity (age) and my deep desire to be part of the solution since the death of my son 20+ years ago, I have witnessed/experienced huge shifts, transformations, and an authentic acknowledgment that “we must do better”. This has been the fuel that has driven so many of us to stick with it. It also helps us to be bold enough to move the goal posts even further as we move forward.

The change that I am referring to has progressed slowly over decades. The concept of engaging people with lived/living experience and their families and/or caregivers started as a loosely defined but strong movement. **A shifting of mindsets had to happen.** And that has happened, very gradually.

I started to witness and sense acceptance that change had to happen. Embracing change. Slowly but surely, there was momentum and a critical mass that was truly recognizing the value of this type of engagement and partnership. A shifting of culture. Then incredibly, lived/living experience, patient, family, and caregiver engagement became a “thing”.

It moved from a loose concept, progressing through tokenism and many false starts, to something meaningful. Now we are seeing it become a tangible “need to have”. This has occurred through tireless advocacy, and emerging evidence supported by policy. The culture has actually started to change. Remarkable!

Much of that change continues to be driven by the tireless efforts of lived/living experience partners, patients, families, and caregivers, even in the midst of navigating their own health care journeys which can be breathtakingly difficult. While I have seen change happen, I see a significant opportunity for the development of engagement-capable environments that facilitate shared responsibility with clinicians, executive leaders, and others across the health system.

Real culture change means that it's everyone's job to turn this strategy of lived/living experience, patient, family, and caregiver engagement into tangible actions and impacts in the health care system.

My vision for the future is for culture change to be championed by every member of the health care system.

Betty-Lou Kristy, Council Chair

Chair's identified opportunities for 2023-24

- ✓ Consider bold policies and resources that encourage clinicians, executive leaders, and patient, family and caregivers to champion patient, family, and caregiver engagement and partnership.
- ✓ Prioritize engagement and partnership with equity-deserving communities, particularly Indigenous, Francophone, Black, 2SLGBTQI+, and people with disabilities. Apply a health equity, diversity, and inclusion lens to health care transformation.
- ✓ Advance policies and supports that address barriers for the equitable engagement of patients, families, and caregivers.
- ✓ Ensure patients, families, and caregivers are co-designing and partnering on the implementation of critical services and programs that impact them, especially related to mental health and substance use and addictions.
- ✓ Adopt and measure standard key performance indicators for patient, family, and caregiver engagement and partnership with the Council and the broader health system.

The Council is excited for the year ahead and continued opportunities to engage, co-design, and partner with the ministry and health system partners to advance a vision of integrated care.

Appendix: Learn more about the Council members

Betty-Lou Kristy (Council Chair) is a bereaved mother, in recovery for over 20 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 over 15 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. Including completing three to six year terms being a board director for Bereaved Families of Ontario Halton-Peel, Canadian Mental Health Association Halton, Halton Alcohol Drug and Gambling Assessment Prevention and Treatment Services, Glen Mills Co-operative Housing Corporation and Addictions and Mental Health Ontario. She also has training and experience with Children's Aid Society, Big Brothers and Sisters, John Howard Society Youth Restorative Justice, V.O.N Hospice Care/Caregiver programs. And she has completed the Halton Citizen's Police Academy program.

Betty-Lou has received several awards, such as the 2009 CAMH Transforming Lives Award, the 2011/12 Ministry of Health Achievement, Commitment and Excellence Award – Partner Relations for her work with the Expert Working Group on Narcotic Addiction, and the 2016 Support House Employee of the Year Award.

She is the Director of Support House Centre for Innovation in Peer Support. The Centre has been awarded the 2017 Ontario Peer Development Initiative Innovators Award, 2017 AMHO President Shield Award and the 2016 Association of General Hospital Psychiatric Services Celebrating Innovation Award.

Amandeep Kaur is the Chief Operating Officer of the Punjabi Community Health Services (PCHS) located in Ontario Health's Central Region. She is starting the role of PCHS CEO on July 5, 2023. PCHS provides culturally responsive mental health, addiction, geriatric, newcomer settlement, and social services to the local communities.

Her role includes leadership, strategic visioning, media relations, fiscal and statistical management, supervision, and other management responsibilities and she has been active in the non-profit sector for the last 33 years. She co-founded the Integrated Holistic Service Delivery Model that caters to addressing the mental health and addiction issues of the South Asian community.

Amandeep started her career as a frontline staff and worked her way up, upgrading her academic credentials and experience, volunteering, and working with mainstream and community-based organizations over several decades. She has received many awards for her work in domestic violence, has numerous research studies to her credit, and is an experienced public speaker.

She led one of the COVID-19 Voluntary Isolation and Recovery Centres in the Peel Region to stop the spread of COVID-19. Amandeep is a Board Member of the South Asian Health Alliance and an active member of the Ontario Health Central Region Mental Health and Addictions Regional Advisory Table; Substance Use Disorder Provincial Advisory Table; High Priority Communities Strategy (Peel); Regional Community Response Table (Peel); Mississauga and Central West OHT; and Peel/Halton/Dufferin/ Settlement Partnerships Executive Council Immigration Refugee Citizenship Canada.

In addition, Amandeep brings a wealth of knowledge and lived experience as a family member/caregiver to a child with chronic mental health difficulties. She is a cancer survivor who supports innovation and looks forward to continuing working with the Council.

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.

As a veteran of The Royal Canadian Navy, **Dean Valentine** gained his experience, knowledge, and professional competencies through over 25 years of dedicated service to the Canadian Forces Logistics Branch. He has been employed in a vast spectrum of working environments both domestically and internationally, providing Human Resource Management and financial support services. Dean was medically released from the Canadian Forces in 2014. He has made Toronto his home and has settled into the community with his partner and daughter.

Dean wishes to disclose and identifies as a member of the LGTBQ2+ community living with and affected by HIV/AIDS and complex PTSD mental health illness. It is his personal journey, both successes and challenges, since being diagnosed in 2008, which has inspired his commitment to community building through engagement with initiatives that improve navigation of our health care networks.

Dean is actively involved in research and engagement projects and has participated with a variety of peer support programs in mental health and addictions. Some areas of passion include Community Engagement, Community Reinforcement Approach therapy facilitation, and Harm Reduction models and their impact on better community health outcomes for vulnerable populations.

Dean is a current member of the Board of Directors at Casey House Hospital and Casey House Foundation. He has been actively involved with the development of the Downtown East Toronto Ontario Heath Team (DET OHT) as a Community Member partner. Dean is a member of the DET OHT Core Group (leadership table) and the Chair of their regional Community Advisory Council. Dean is a passionate advocate of establishing mindful holistic approaches to patient-centred care where the patient, family and caregiver voice is at the forefront of its decisions and an equitable member in its leadership team.

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 and 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's 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.

In addition, 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.

Joan Duke is living in Thunder Bay, where she grew up, but for much of her adult life she lived in rural Northwest and Northeast Ontario. Working and living in the North has given her a clear picture of the need for the patient, client, family, and caregiver participation in this positive work for change.

Family and personal chronic health conditions and the quest for treatment helped her to understand the pros and cons of the health care system. As a volunteer at the Thunder Bay Regional Health Sciences Centre, she chose to become involved in their Patient and Family Advisory Committee.

Joan joined committees for the Research Institute and from there branched out to quality control, policy, and other areas in the hospital. In responding to the challenges of COVID-19, Joan has joined several advisory roles, including the Council, at Ontario Health, and in Northwestern Ontario Health Committees, and is presently involved in committees for the formation of the City and District of Thunder Bay OHT. Her experience also extends to national committees.

Again, as before COVID-19, Joan considers herself a community volunteer and is actively involved in community organizations such as Age Friendly Thunder Bay and the Thunder Bay 55 Plus Senior’s Centre. Her work extends to charity events that donate funds to various cultural organizations and to independent groups that donate to health agencies. These activities allow her to talk to and explore how the people in the community are feeling and thinking about their experiences with the health system. Joan passionately believes that every health agency and group should have a very robust program to encourage patient engagement. There is no better way to get the fresh outlooks and ideas for positive change than from those that have the experience – the patients, the families, and the caregivers.

Kimberly Cato is the founder and Chief Executive Officer of True Roots Counselling Services where she assists those blindsided and/or overwhelmed by life-altering circumstances. Kimberly is a registered psychotherapist who brings over 30 years of experience providing trauma responsive and asset-based services through an anti-racism, anti-oppression, social justice, and somatic abolitionism lens. Her analysis also centers intersectionality, as she is a Black woman who engages with the world from a wheelchair.

Kimberly utilizes a range of therapeutic practices, such as Africentric and non-traditional ways of transformative change, that incorporate music and arts. Kimberly is exceptionally skilled and certified in cognitive behavioral therapy, Motivational Interviewing, Tree of Life, and various narrative therapies.

Kimberly’s commitment to healing and mental wellness is long-standing. As a former Chaplain for a community-based hospice in Toronto, Kimberly is familiar with journeying alongside palliative individuals, families anticipating grief, and communities negatively impacted by loss through these life-altering transitions. These experiences empowered her during the many years she spent as the primary caregiver for both her mother and father who were diagnosed with Alzheimer’s disease.

In 2020, during the wake of George Floyd's public murder and the resulting global racial reckoning, Kimberly launched Check-In and Chat, a weekly support group for racialized women. She also started a parallel group for racialized men, which is a monthly peer decompression space called The Men’s Edition. She is delighted to be a part of the esteemed Council’s collection of passionately engaged individuals working together to ensure Health Equity is the common experience of all Ontarians.

Sandi Bell Sandi Bell is the President of EMPOWWORD Inc, a mediation, training and development firm. She has an extensive background dealing with interpersonal and organizational conflict, human rights, social justice, anti-racism and anti-oppression, child welfare, accessibility, disability issues and equity / diversity / access / inclusion. Sandi is a part-time Commissioner with the Ontario Human Rights Commission and a Member of the Human Rights Legal Support Centre.

The entirety of her professional and volunteer endeavours have all, in one way or another, been in pursuit of equality, human rights, social justice and inclusion for diverse and marginalized communities. With well over 30 years of experience in the areas of human rights, anti-racism, anti-oppression, and equity, she has worked closely with many different equality-seeking communities. The totality of her experiences offer her great insight into the experiences and impacts of discrimination.

Her work in disability rights has been extensive and in many different areas. During her 12 years as a school Trustee in Hamilton, she spearheaded a number of initiatives which included advocacy flowing from Bill 82 to ensure that children with disabilities previously denied public education were welcome.

She was a member of the Mental Health and Law Advisory Committee of the Canadian Mental Health Commission, and more recently, was appointed Chair of the AODA Health Care Standards Development Committee which was tasked to recommend accessibility standards for Ontario hospitals to reduce and prevent barriers in health care to the Minister of Seniors and Accessibility and the Minister of Health.

She also served for two terms as part-time Commissioner for the Canadian Human Rights Commission. In her roles as a rights educator, mediator, Commissioner, and a member of the Immigration and Refugee Board, she gained a more fulsome understanding of the access to justice barriers that many individuals who experience discrimination routinely face.

Sandi proudly self identifies as a Black Indigenous woman with disabilities. Her passion to rid society of and prevent racism, discrimination and oppression is more than a topic or research project; it is a way of life.

Sandra Holdsworth's health care journey and dedication to co-design was truly launched in earnest when she received a liver transplant in 1997. After several years of going undiagnosed with a rare liver disease and Crohn's disease, she also required a permanent ileostomy in 2012. Sandra's lived experience continued with melanoma, which she was fortunate to have received early intervention, an ADHD diagnosis in her fifties and she currently lives with chronic kidney disease, due to long-term immunosuppression medications.

Sandra soon began using her experience as a liver recipient to advocate for organ and tissue donation and has helped others requiring a transplant on their healthcare journey. This work naturally grew into an interest in research and the healthcare system and how by partnering with patients we can align research with patient priorities and improve the patient experience.

For the last decade, Sandra has been actively engaged 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, recruits, and assist with knowledge translation. She was on the Steering Committee of CanRestore, where they implemented several clinical research projects on exercise and rehabilitation in transplant. Sandra has been a patient partner on several research projects, has completed peer reviews, and has been listed as an author on position papers. She has been a co-applicant on published research projects and is currently working on projects related to engagement evaluation and AI and Machine Learning.

Sandra has also been an advisor to Health Quality Ontario, now Ontario Health, for several years and was a Patient Advisor for Health Standards Organization on their Acute and Critical Care Technical Committee. Sandra is actively involved with the Ontario SPOR Support Unit, Patient Partners Working Group and is an active board member of the Patient Advisors Network, which partners with the Centre for Digital Health Evaluation, where Sandra is a Patient Partner Evaluator.

In addition to her dedication and passion to health care engagement and co-design, Sandra had a 30-year career in the banking industry in various managerial roles, before she semi-retired. Following that and before becoming fully engaged in health system co-design, she completed a contract position with Canadian Blood Services as an Event Coordinator and spent two years with Hospice Muskoka as their fundraising and events coordinator.

Since the creation of Ontario Health Teams four years ago, Sandra has been a Patient Partner on the Muskoka and Area Ontario Health Team Collaboration Steering Committee. She is also the Co-Chair of the Patient Family and Care Partner Advisory Council and the patient, family /caregiver representative on the Alliance Council. Her work with Ontario Health Team's has expanded to be on the OHT patient, family and caregiver community of practice planning group at the provincial level and the OHT Learning Series Steering Committee. Recently Sandra was asked to be a member on the OHT Service Transformation Committee led by Ontario Health.

Sandra is active in her community as a volunteer for Gravenhurst Against Poverty as a Communications Assistant and is the Co-Chair of Ignite Gravenhurst.

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/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 struggling with mental wellness and eating disorders, Shannon has experienced first-hand frustration with the lack of sustainable and supportive systems for youth struggling with mental health. From that first closed door through the countless times she supported families and youth during crises as a high school administrator, she knew she needed to become an agent of change.

As a result, Shannon is strengthening her capacity as a citizen leader and researcher as she finishes her Master of Youth Mental Health from Orygen in Australia. Equipped with the latest research, she shamelessly advocates for co-designed, inclusive, and culturally safe community mental health and substance use services addressing rural Ontario's social determinants of health in her work with Health Standards Organization's Improving Integrated Care for Youth Grant, as Project Manager for The Grove (Youth Wellness Hubs Ontario), and as the Founder and President of The Well Community Collective.

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 and Principal Lead of STR Consulting where she has developed, led, and facilitated training and education on conflict mediation, violence prevention, equity, and anti-oppression, to name a few. She has extensive knowledge working with youth, Indigenous, 2SLGBTQI+, violence against women, and racialized communities.

Shequita has extensive experience with adult and youth development and education, and excellence at working from an anti-oppression/anti-racism framework and challenging anti-Black racism. She holds an Honors BA 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 into 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.

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

Sterling Renzoni is studying biochemistry and molecular biology at Trent University. He has battled anxiety and perfectionism for as long as he can remember. In grade 9 these traits morphed into an eating disorder. This led Sterling to spend his high school years in and out of hospitals and outpatient treatment battling an eating disorder.

When he finally received the treatment he needed, the COVID-19 pandemic struck, and he had to recover from his eating disorder with the added mental health challenges associated with the pandemic.

Throughout Sterling's patient experiences, he was able to appreciate its strengths and where there was need for growth. He knows first-hand the pain of battling a debilitating mental illness and fighting to access the appropriate care. After recovering from his eating disorder, Sterling has channeled this pain into passion, becoming an established mental health advocate.

Sterling has continued to raise awareness about and advocate for those with mental illness, including through Trent Active Minds, EDify Talks, the Stigma-Free Society, the Patient Advisory and Recovery Committee at Ontario Shores, Health Quality Ontario (now Ontario Health), the Cleverly Lab, the SickKids Foundation, and the Yellow Tulip Project, as well as various media outlets.

Sterling is committed to transforming the health care system so that patients won't need to battle the system in addition to their illness to get the help they need. Sterling is honoured to have the opportunity to work among such a distinguished group of members in the Council and is excited for the work that lies ahead.

Wendy De Souza is a cis Latinx woman and first-generation Canadian with Indigenous ancestry in Brazil. With a decade of experience as a public educator, prolific public speaker, and community mobilizer, she is driven by her passion for community development and facilitating transformative spaces through decolonizing our collective ways of knowing.

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 experience with community engagement, 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, 2SLGBTQI+, Muslim, racialized, and newcomer communities in violence prevention and community economic development initiatives.

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, Non-binary and Trans communities, and training resources for senior leaders in organizational equity.

Wendy has lived and family experience navigating complex birth issues, mental health, ADD/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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