Moving forward together: **Transforming care through partnership and engagement**

Minister's Patient and Family Advisory Council

Annual Report **2021-22**

Ontario

Land Acknowledgment

We acknowledge that the Minister's Patient and Family Advisory Council 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 are now home to many diverse First Nations, Inuit and Métis peoples.

Long before today, Indigenous peoples have been the stewards of these lands. We also 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.

We recognize that these lands, both historically and currently, have been the home and gathering place of many Indigenous people from various Nations from across Turtle Island. We are grateful for the opportunity to also live, work and meet in this territory. We show our respect to the Indigenous peoples of this land, today and all days.

We stand in solidarity with murdered and missing Indigenous women, girls, transgender and Two-Spirited people, and we affirm our commitment to heartfelt reconciliation.

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A message from **Christine Elliott**

Deputy Premier and Minister of Health

It is my privilege to accept the inaugural report of the Minister's Patient and Family Advisory Council (the "Council") for 2021-22. As the Minister of Health, I am firmly committed to transforming our health care system to one that is focused on the needs of patients, families and caregivers. Patient-centred care should be the foundation of our health care system. The ongoing engagement and partnership of patients, families and caregivers is an important part of how we bring these values into action.

I am dedicated to advancing a connected health care system for everyone in Ontario — a system that is co-designed with patients, families and caregivers so that their experiences and outcomes can be improved. To support this goal, this government established the Council as a permanent advisory agency in 2019. Since then, the Council has enabled true engagement and partnership with patients, families and caregivers.

Betty-Lou Kristy's work as the Chair of the Council has been truly remarkable. Her leadership, resilience and strength are truly inspiring. Betty-Lou has guided the assembly of a remarkably diverse Council, rich in its variety of perspectives and experiences and united in a shared commitment to patient, family and caregiver-centred care. She and I meet frequently to discuss our shared goals, and I am so pleased with how much the Council has achieved to date.

The Council has made significant contributions to shaping patient care in Ontario over the past year. For example, they updated the *Patient, Family and Caregiver Declaration of Values for Ontario*, and provided strategic advice on digital health, home and community care and mental health and addictions. They have also advised on the delivery of integrated and co-ordinated care through Ontario Health Teams. The Council's contributions on these topics also factored in their lived and living experience as patients, families and caregivers managing significant challenges brought on by the COVID-19 pandemic.

I would like to extend my sincerest appreciation and gratitude to the exceptional members of the Council: 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. I am very privileged to have the opportunity to work with and learn from them.

I am so impressed with the collaboration, commitment and thoughtfulness that the Council has demonstrated over the last year. Their remarkable work over 2021-22 speaks to the true value of prioritizing the needs of patients, families and caregivers as we transform the health care system.

Christine Elliott

Christine Elliott
Deputy Premier and Minister of Health

A message from **Betty-Lou Kristy**

Chair, Minister's Patient and Family Advisory Council

I have to be honest — I am not sure how to approach this message. So many people are experiencing so many things right now. The pandemic and its impacts continue to persist. The opioid overdose epidemic continues unabated. Mental health and trauma are cascading, and for many, grief, loss and bereavement are manifesting in real time. Collectively as a society, and individually as humans, we are having to negotiate changes that we do not seem to have any control over.

So why would my opening remarks be so fundamentally honest? Because this is our reality. We are living through this together, but in different ways. Through all of this, health care has been going through massive transformation. We've recognized that our system was not serving all of us in equitable ways and in some cases causing actual harm. This has become the pivotal catalyst for change.

I have personally experienced a litany of harms. The death of my son to opioid overdose was the harm that has inspired my work. Yet I also recognize there are extraordinary people and phenomenal services within our health care system and our society. These people and services continue to be our North Star.

There is a growing role for people who have engaged with health care services to share their life journeys to help guide our discussions toward health care transformation. Patient, client, lived/living experience, family, caregiver, resident and citizen voices are essential links to drive meaningful change. A large piece of this change goes well beyond health care parameters and is more about social change. It is where health care intersects with the broader social determinants of health and what people need to find their wellness — whatever that looks like for each person.

There is a need to humanize health care, to model recovery/wellness and promote resiliency. At the same time, we must also speak to the significant system and service barriers, the unmet needs and the significant harms due to discrimination, bias and judgement (stigma). We need to ensure every person will be recognized, appreciated and respected for who they are and their unique journey. We also need to ensure that we can adapt the care we provide to the level of people's wellness and self-identified needs.

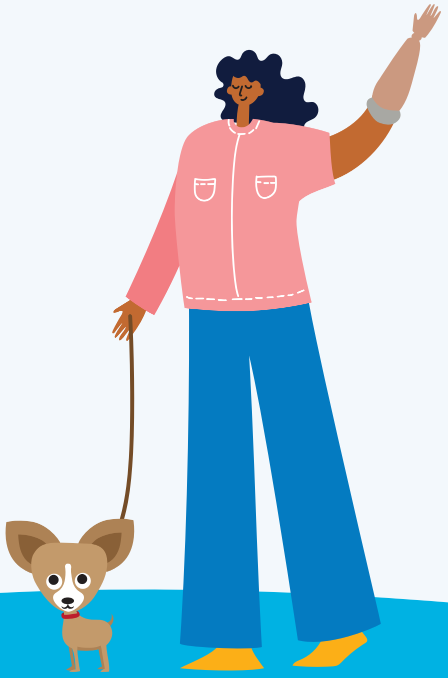
To me, health care needs to be about connection. Not only across the spectrum of physical care, but also in terms of mental health, addiction, substance use disorder, loss, grieving and bereavement. Considerations such as quality of life, informed choice, respite, living "well" with chronic conditions and/or dying with dignity at home are all included. We need high-quality, integrated care, provided by a healthy, thriving workforce that prioritizes kindness, compassion and empowerment. We all need to feel valued, respected and treated in a dignified and empowering way. That is what nurtures hope, resiliency and healing.

Being the Chair of the Council since June 2020 is an ABSOLUTE HONOUR and provides more opportunity to empower others to champion change. I'd like to express my appreciation and thanks to the Council for their many contributions to improving the patient, family and caregiver experience in Ontario. I am humbled by their expertise, passion and determination. They have vast networks and proven abilities to conduct community outreach that keep our advice grounded as we work to advance systems-level transformative change. The Council excels in their ability to share space with each other, value each other, negotiate consensus and hold each other in unconditional high regard. That extends to all interactions with all stakeholders who come to the Council for advice.

As Chair, I'm thrilled to continue building and leveraging connections between the Council and sector partners to help improve patient care and experience, and to ensure the voices of patients, families and caregivers are at the centre of health care system planning.

Together we can rebuild and co-create solutions. Together we can demonstrate the art of possibility. Be curious. Humanize. Innovate. Emerge.

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



> ***"I think my appointment speaks volumes about this government's commitment to mental health and addiction. It feels like a huge blending of lived and family experience, years of advocacy, learning what the system needs and working hard to be part of the solutions."***
>
> —Betty-Lou Kristy, Chair, Minister's Patient and Family Advisory Council

PETE'S RABBIT – A HUMAN NARRATIVE FOR HOPE

The Art of Possibility - Listen, REALLY, Listen

My late son Pete lived in my basement, in what we now call a man-cave. We had a unique and beautiful relationship. We were (are) perfectly imperfect. Pete's unique sense of humour and general "weirdness" truly entertained me, and we found great solace from our struggles and lots of laughter despite all the challenges.

Pete's love for animals was incredible. One day, when he was about 23 years old, he ran upstairs and said, "Mom, come quick! There's a rabbit outside in the backyard." So, I ran down and, voilà, there was NO rabbit. I turned to Pete and said, "Nice one, Pete." He laughed and said, "No, Mom, really, there was the cutest rabbit here and he stayed for a long time." Of course, I was the dutiful mother who ran back downstairs many times after that only to find NO rabbit, again and again. It finally got to the point that I would yell back (no longer making the journey downstairs), "Yeah right, Pete!" Pete would laugh and insist that he was not imagining the rabbit. We had great fun with this.

One day, a year after Pete died, I found myself begging my son to send me a sign. I came downstairs to sit in his basement — and there in the middle of the backyard was his rabbit! The rabbit sat majestically on its hind legs, with its head and paws up looking straight at me. That is when I knew that Pete and I were meant to do something meaningful with his death. That is when I started my journey of being a lived experience/family advocate and peer.

And, yes, Pete's bunny has come back to visit me many times over the years.

Thank you to my team

I want to thank the Patient Engagement Secretariat at the Ministry of Health, which supports both me as Chair and the Council as a whole. There is an incredible amount of work, co-ordination 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, Kevin, Michelle, Nikita and Joyce 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. I would also like to extend a huge thank you to Minister Elliott and her team. The Minister's commitment to authentic patient, family and caregiver partnership and cultivating a genuine relationship with the Council is truly inspiring. I meet with Minister Elliott monthly and am thrilled to have the opportunity to engage in open and meaningful dialogue as we collaborate to advance this integral work.

Inclusive language for a patient, family or caregiver

The spectrum of Ontarians in contact with the health care system is vast and multifaceted. In this report, the term "patient" is inclusive of those who identify as lived/living experience, client, citizen, resident, community member and others who 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 biological family, self-identified family, as an informal caregiver or as a friend.

About the **Minister's Patient and Family Advisory Council**

Established as a permanent provincial advisory agency in 2019, the Minister's Patient and Family Advisory Council is made up of patient, family and caregiver experts who provide advice to the Minister and Ministry of Health. The Council helps to improve patient care by ensuring that the voices of patients, families and caregivers are at the centre of policy development and decision-making at the Ministry of Health. The Council is a key advisory body in support of health care system transformation. Its ongoing work speaks to the importance of partnership and co-design with patients, families and caregivers across all levels of the health care system.

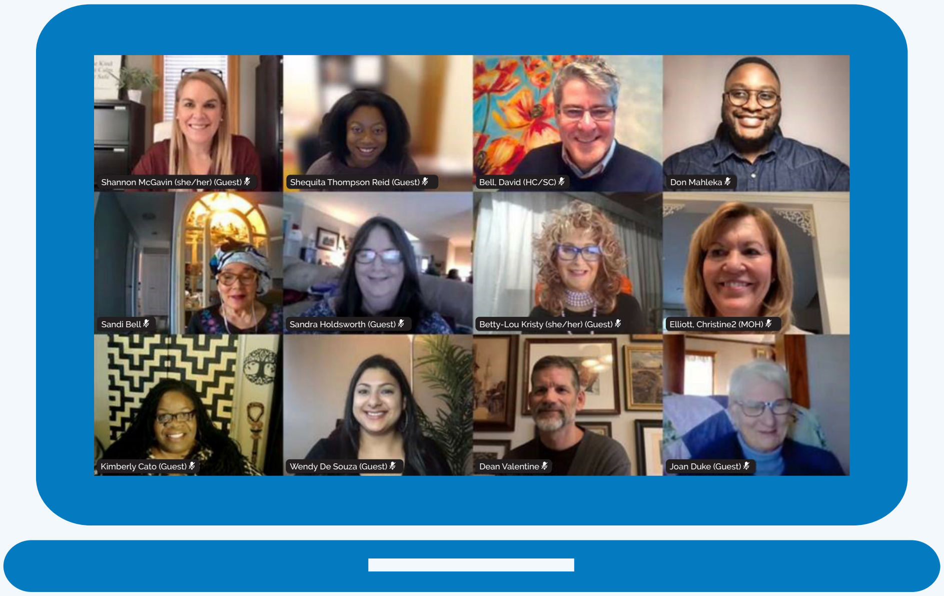
The Council embodies a wide range of lived experiences and perspectives. Members have been recruited through a values-based approach, focused on respect and collaboration. Members were interviewed through a process that was led and co-designed by the Council Chair, Betty-Lou Kristy. A priority was to establish a safe, inclusive and collaborative process to recruit patient, family and caregiver advisors for the Council. A thoughtful and phased approach to member recruitment helped to ensure that the Council reflects the skill sets, diversity, lived experience and/or family, caregiver experience needed to advise on health care systems and health care transformation.

The Council follows a trauma-informed approach that emphasizes self-care for members in their advisory work. All members have committed to take care of themselves and each other during discussions and to acknowledge when a conversation may have affected them. See Appendix A – Self-care and wellness support for Council meetings/consultations.

The Council has also developed and adopted a Code of Conduct outlining guiding principles and core values rooted in the ethics of respect, collaboration, inclusiveness and innovation. See Appendix B – Code of Conduct.

Council Members 2021-22

The Council currently has 13 patient, family and caregiver advisors, including the Chair. Together, they bring a diverse range of skills and lived experience from across the province.



Minister's Patient and Family Advisory Council Meeting, January 13, 2022, engagement on Digital Health.

Council members missing from screenshot:

Amandeep Kaur

Sterling Renzoni

Council Members on screen (left to right) Top Row: Shannon McGavin, Shequita Thompson-Reid, David Bell, Don Mahleka. Middle Row: Sandi Bell, Sandra Holdsworth, Betty-Lou Kristy (Chair), Christine Elliott (Minister). Bottom Row: Kimberly Cato, Wendy De Souza, Dean Valentine, Joan Duke

Council's expertise, focus 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 & 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 & Empowerment, Community Engagement, Virtual Care, Digital Health, Policy Review, Quality Control, Research

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

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 & 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 & Addiction, Two Spirit, Nonbinary and Trans Communities

See Appendix C for full member biographies

BY THE NUMBERS

Over **400 candidates applied to the Council.**

There are more than **1400 patient, family and caregiver advisors** in the ministry's virtual pool of patient, family and caregiver advisors.

The Council Chair participated in **30 virtual visits with Ontario Health Teams** as part of OHT intake/assessment process, **providing recommendations to the Minister** and to support OHTs as they implement engagement and partnership strategies.

To date, the Council Chair participated in approximately **630 hours of collaborative partnership and co-design work** across the Ministry and Ministry partners.

The Council members and Chair have spent more than **900 hours on meaningful Council engagement and co-design** in health care transformation.

Advisory work of the Council 2021-22

The Ministry of Health (the ministry) works together with the Council to ensure patient, family and caregiver insights inform health care system planning and policy development. As partners, the Council and the ministry are committed to the principles of meaningful co-design, equity, diversity, learning, respect, inclusion, responsiveness, and transparent and effective communication.

The work of the Council in 2021-22 has spanned several key areas of health care system transformation and the government's plan to better connect care for Ontarians:

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

Through frequent engagements with the Council, the ministry gains insights and feedback on policies and programs early in their formation, during development and through to implementation. The ministry uses a feedback loop to connect back with the Council on the impact of their advice. The Council and ministry also partner with Ontario Health to ensure ongoing engagement and alignment. For example, Ontario Health has been a key partner with the Council in discussions on Ontario Health Teams.

Patient, Family and Caregiver Declaration of Values for Ontario

The *Patient Declaration of Values for Ontario* was authored by the inaugural Council through extensive consultation with patients, families and caregivers across the province. The Declaration was originally released in 2019 and has been held up as a foundational document for the health care system. Current Council members shared this recognition, while still identifying select updates they thought were important to advance.

On September 17, 2021, an amended version of the *Patient Declaration of Values for Ontario* (renamed the *Patient, Family and Caregiver Declaration of Values for Ontario*) was released. The Council's updates to the Declaration emphasize the importance of equitable access to health care services and the identification and removal of systemic barriers that contribute to inequitable health care access and outcomes.

The Declaration is grounded in a vision of a health care system where patients, families and caregivers are recognized as active partners in their care. The Declaration provides a framework that can be used to develop policies, programs and services that advance patient-centred care.

The *Patient, Family and Caregiver Declaration of Values for Ontario* serves as a compass for the individuals and organizations involved in health care. It provides a summary of the principles and values that patients, families and caregivers identify as important to them. These include:

- Accountability
- Empathy and compassion
- Equity and engagement
- Respect and dignity
- Transparency

Please see Appendix D - *Patient, Family and Caregiver Declaration of Values for Ontario*.

> “The Minister’s Patient and Family Advisory Council has informed our work across a number of transformation initiatives. Our team relies on the lived and living experience and insight of the members to bring a patient, family and caregiver focus to improving the quality, experience and equity of access to care across Ontario.”
>
> —Amy Olmstead - Executive Lead, Ontario Health Teams Division

Ontario Health Teams (OHTs)

Ontario Health Teams are a new approach to health care that brings together health care providers to work together as collaborative teams to better connect care for patients, families and caregivers. OHTs were established as part of Ontario’s plan to end hallway health care and build an integrated health care system focused on the needs of patients, families and caregivers. Patient, family and caregiver engagement and partnership is a foundational building block of the OHT model. The Council serves as a key advisory body on the work of OHTs as they progress toward maturity in engagement, partnership and co-design with patients, families and caregivers. Examples of engagement include:

- Several members of the Council are leaders within their local OHTs and/or participate in broader provincial groups such as OHT Communities of Practice for Patient, Family and Caregiver Engagement and Partnership.
- An OHT Subcommittee of the Council meets quarterly. They provide advice on how to support OHTs to embed patient, family and caregiver engagement and partnership now and as teams mature. The Subcommittee has contributed to the development of resources and strategic guidance that reflects leading practices.
- The Council was a key partner in the development of provincial guidance for OHTs on the *Patient, Family and Caregiver Declaration of Values for Ontario* as well as the *Patient, Family and Caregiver Partnership and Engagement Strategy* (outlined below).

Further engagement with the Council will focus on the maturation of OHTs including expectations that ensure meaningful partnership and supports that OHTs will need to meet these objectives.

OHT Patient, Family and Caregiver Partnership and Engagement Strategy – Provincial Guidance Document

As part of their early deliverables, approved OHTs are asked to develop a *Patient, Family and Caregiver Partnership and Engagement Strategy* outlining their plans to establish and advance patient, family and caregiver partnership and engagement structures within their local setting. Guidance was provided to OHTs *(Patient, Family and Caregiver Partnership and Engagement Strategy: Guidance for OHTs)* to support the development of their strategies and was built with input from Council members. Through this contribution, the Council played an integral role in shaping expectations for OHTs as they partner with patients, families and caregivers.

Patient, Family and Caregiver Declaration of Values for Ontario – Provincial Virtual Engagement Series Webinar for OHTs

The Council designed and hosted a Virtual Engagement Series Webinar (held on September 27, 2021) to guide OHTs in their adoption of the *Patient, Family and Caregiver Declaration of Values for Ontario*. Adoption of the Declaration is a requirement for all approved OHTs. Council members who are leaders in their local OHTs shared their experiences in this webinar and their passion for advancing the Declaration locally.

OHT supports and collaborative governance

Additional Council advice on OHTs has focused on how to effectively support OHTs to partner and engage with patients, families and caregivers now and as they mature. This has included targeted advice on how to:

- more easily access supports and resources
- better support OHTs to learn from each other
- strengthen the voice of patient, family and caregiver partners in collaborative decision-making

Home and Community Care

The Ministry of Health is working to modernize the delivery of home and community care services. This includes working to update the relevant legislation and regulations. Engaging patients, families and caregivers throughout this process has been crucial to understanding how Ontarians experience the existing system. This input helps identify barriers and opportunities so that meaningful improvements to the system can be made.

The ministry has developed new home and community care regulations under the *Connecting Care Act* to support more connected delivery of services for patients and families. The Council provided feedback on the ministry's proposed approaches, including:

- the scope of home and community care services
- requirements for care coordination
- factors to be considered during care planning
- complaint processes
- the Bill of Rights

Through the Council's feedback, several changes were made to the proposed regulations. To give just one example, under the Bill of Rights, a patient now has a right to: designate a family member or other person to be present and participate with the patient in assessments, care planning and coordination of services and receive clear and accessible information about their assessments, care plans and services.

In addition, the ministry developed the *Ontario Provincial Framework for Palliative Care* along with a report on the status of palliative care in Ontario. The overarching goal of the Framework is to support and improve the quality of and access to palliative care. The ministry consulted the Council to better understand the current palliative care system, such as:

- how Ontarians experience palliative care
- the degree to which the current system meets the needs of patients, families and caregivers
- barriers to and opportunities for allowing patients to spend their final days at home

In their feedback, Council members emphasized the need for clarity on definitions of palliative and end-of-life care, continuity of care, cultural safety, respect for individual and family member preferences, as well as increased support for patients with long-term and complex symptoms, including children with life-limiting illnesses.

Mental Health and Addictions

In March 2020, the province released its mental health and addictions strategy, *Roadmap to Wellness*. Under the Roadmap, Ontario has announced $525 million in new base funding for mental health and addictions services.

Many Council members have identified lived and living experiences with mental health and addictions. Many Council members are also family/caregivers supporting a person with mental health and/or addictions needs. In dialogue with the ministry, the Council has stressed the need for more efforts to address gaps in this sector. Members have noted a particular sense of urgency due to the ongoing impact of the COVID-19 pandemic.

They shared these experiences to help shape the implementation of the mental health and addictions strategy in a number of concrete ways. The Council provided:

- Recommendations on reducing barriers to accessing mental health and addictions services
- Feedback on the need for services among specialized populations (e.g., first responders, youth, seniors, rural Ontarians), while ensuring cultural safety is considered
- Perspectives on the importance of supporting and engaging families and caregivers at every step of the care journey, and the integral role families and caregivers play in supporting the care of their loved ones

In support of these contributions and in alignment with the *Roadmap to Wellness*, the ministry continues to consider opportunities to fund services that meet specialized needs of people in ways that are culturally safe and appropriate. This includes moving ahead with the system transformation work of the Roadmap that will create more accessible services and reduce system barriers. It also includes addressing wait times and increasing access to mental health and addiction services.

Call to action for future advisory work

The unprecedented circumstances of the COVID-19 pandemic have highlighted the significant challenges Ontarians face when attempting to navigate, access and connect to mental health and addictions services. The Council recognizes the significant need for patient, family and caregiver advisors to contribute their lived, living, family and caregiver experiences and perspectives to address mental health and addictions system challenges. Council members will continue to advise on the implementation of the *Roadmap to Wellness* with consideration to the ongoing impacts of the COVID-19 pandemic, working with the ministry, Ontario Health and the Mental Health and Addictions Centre of Excellence within Ontario Health.

Data and digital health

The Council and the Ministry of Health are committed to helping advance a digitally integrated, data-driven health care system in Ontario that is truly focused on the needs of patients, families and caregivers. To support these efforts, the ministry regularly engages with the Council, including through a dedicated Digital Health Subcommittee.

Through the *Digital First for Health Strategy*, the ministry has sought the Council's input in helping to shape several patient-facing digital health initiatives. These include:

- digital health solutions for virtual care
- online appointment booking
- making it easier for patients to access their health information as already permitted under the *Personal Health Information Protection Act* (PHIPA)
- implementing digital identity mechanisms
- supporting efforts to make it easier for Ontarians to digitally engage with the health care system

The Council provided valuable perspectives drawn from lived experiences on the preferences, challenges and expectations of individuals in the collection, use and governance of health data. The Council's advice included recommendations to address the distinct needs and perspectives of different communities and patient, family and caregiver groups, especially those impacted by technological barriers and health inequities related to the social determinants of health. Council members emphasized the importance of continuing to prioritize equitable and standardized access to personal health information. They advised engaging with neighbourhood, grassroots and community organizations for context-specific and culturally sensitive insights for digital health solutions and health data governance.

In addition, in response to the Council advice, the ministry is considering ways to work with providers and other stakeholders to promote health literacy to ensure that patients, families and caregivers understand their personal health information. Further considerations from the ministry will include how patients can use their data through innovative technologies to generate insights into their health status.

> ***"The Digital Health Division greatly values our routine engagements with the Council. Their input allows us to implement the Digital First for Health Strategy while accounting for the advice, perspectives and lived experiences of Ontarians."***
>
> —Greg Hein – Assistant Deputy Minister, Digital Health Division

Work of **the Council Chair**

As Chair of the Council, Betty-Lou Kristy serves as leader and strategic advisor to the Minister and the Ministry of Health on strengthening and expanding patient, family and caregiver engagement and partnership across the health care system. She has led the work of the Council across all priority areas including the release of an amended *Patient, Family and Caregiver Declaration of Values for Ontario*. She has also led recruitment efforts to ensure a diversity of skills and lived experience on the Council.

Betty-Lou has chaired and held leadership positions on ministry and Ontario Health governance advisory groups to support patient, family and caregiver perspectives in policy making and program design. Her stewardship and dedication to patient, family and caregiver partnership is well known across the ministry and in the health care sector.

Betty-Lou remains a vocal advocate and brings the values of co-design and partnership to every engagement with the ministry and health care system.

Committees and working groups

The Chair's engagement in a number of strategic planning areas builds the partnership between the Council and its health care partners, and brings a patient, family and caregiver perspective to major initiatives in health care for Ontario:

- Member of the Mental Health and Addictions COVID-19 Recovery Advisory Table. Also a member of the newly created Leadership Advisory Committee within the Mental Health and Addictions Centre of Excellence
- Member of the Public and Patient Engagement Collaborative working group focused on the development of a standard tool to evaluate patient, family and caregiver engagement within OHTs and across Ontario's health care system
- Co-chair of OHT Patient, Family and Caregiver Engagement Supports Working Group. The group meets monthly to ensure continuity, coordination and access to supports for OHTs
- Member of the Executive Steering Committee for the provincial Health Care Navigation Service. This committee provides oversight on the development of a digital tool to help Ontarians navigate the health care system
- Ex-officio member of the Ontario Health Data Council. This is a key provincial table that provides advice to the Minister of Health on the strategic management of Ontario's health data to foster a person-centred learning health care system
- Member of the Home Care Modernization Table. The Table advises on the implementation of initiatives related to the Ministry of Health's plan to modernize home care delivery

WORKSTREAMS

Since her appointment in June 2020, Betty-Lou Kristy has been engaged and provided advice on many health priority initiatives.

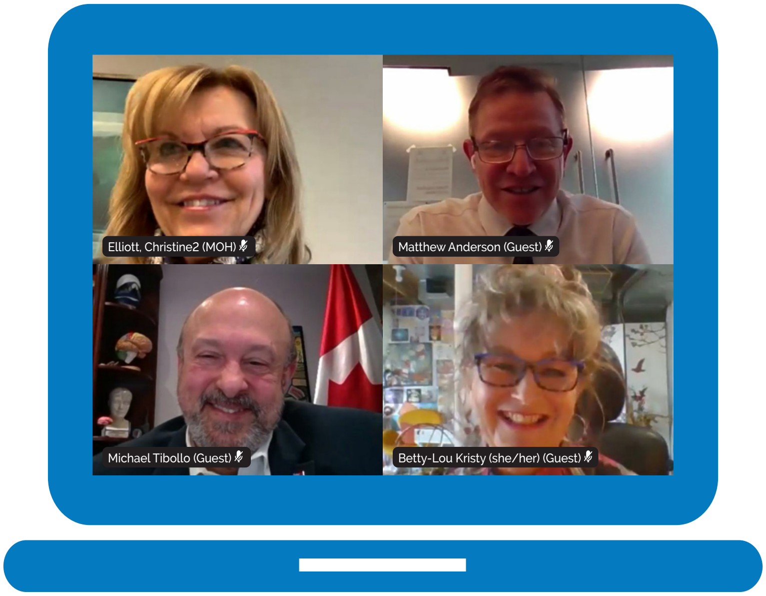
Advising the Minister of Health: Betty-Lou and Minister Elliott engage in monthly one-on-one meetings to discuss the current work of the Council, achievements and issues of importance for patients, family and caregivers.

Building and leveraging connections with Ontario Health: Betty-Lou plays a foundational strategic role in strengthening and expanding patient, family and caregiver engagement efforts in Ontario. Working in partnership with Ontario Health and other health care system entities, Betty-Lou continues to advise on efforts to enhance and align engagement activities across the broader health care system to maximize their quality and impact.

Supporing OHT intake and assessment: Since September 2021, Betty-Lou has joined in 30 virtual visits to assess OHTs. This includes assessing the OHT's patient, family and caregiver partnership and engagement efforts, and making final recommendations to the Minister. Betty-Lou has also visited with OHTs to support their engagement and partnership strategies.

Engaging OHTs and health care system partners: Betty-Lou provides lived and family/caregiver experience perspectives and guidance on leading practices for patient, family and caregiver engagement through provincial webinars, sector conferences and ministry working group meetings.

Collaboration and co-design across partners: Betty-Lou has worked to establish connections with a wide range of OHTs and patient, family and caregiver experts and advisory council members. These include Ontario Health, the Ontario Caregiver Organization, the Public and Patient Engagement Collaborative, Rapid-Improvement Support and Exchange, the Emergency Health Services Division of the Ministry of Health, the Patient Ombudsman and the Psychiatric Patient Advocate Office.



Mental Health and Addictions Action Planning Session (Top Left to Right) Deputy Premier of Ontario, Minister of Health Christine Elliott; Ontario Health CEO Matthew Anderson (Bottom Left to Right) Associate Minister of Mental Health and Addictions, Michael Tibollo; Minister's Patient and Family Advisory Council Chair, Betty-Lou Kristy. Date April 7, 2021.

Moving forward – Closing remarks from the Chair

Transforming the health care system is complex, dynamic and takes time. However, great strides continue to be made every day in helping to strengthen patient, family and caregiver engagement and partnership.

As we continue to advance in system co-design, it is important to do so in a trauma-informed way. A trauma-informed approach helps create a safe space, recognizing that patients, families, caregivers and other stakeholders may have a history of trauma.

As we look towards the future, there is a growing role for people who have engaged with health care services to share their life journeys. We will continue to listen to their insights and experiences to help guide our efforts to transform the health care system. There are new voices to be heard, including patients, clients, those with lived and living experiences, families, caregivers, residents and citizens. These voices are essential if we want to hold conversations that will drive meaningful change.

The Council has identified a specific opportunity in 2022 for greater participation of patients, families and caregivers to inform the co-design and implementation of mental health and addiction services and supports in Ontario through the *Roadmap to Wellness* strategy. As the province continues to address the impacts of COVID-19 and the opioid overdose epidemic, this dialogue is critical to inform ministry decision-making.

Advocacy and experiential expertise can have an enormous positive impact across the health care system. It provides a broader perspective grounded in the reality of what truly happens to people — both good and not so good. This is more important now than ever due to the ongoing impacts we face related to the COVID-19 pandemic. Key factors that will be instrumental in the success of our work include:

1. Recognizing and respecting patients, families and caregivers as partners and including them at all stages of planning, design and implementation.
2. Actively engaging patients, families and caregivers with diverse perspectives and living/lived experiences, and actively engaging those who are equity deserving and vulnerable.
3. Considering and addressing barriers to equitable participation.
4. Ensuring that engagement with patients, families and caregivers happens frequently, respectfully and meaningfully across all areas of the health care system.
5. Providing patients, families and caregivers with ongoing supports such as tools and resources.
6. Ensuring that all partners in the co-design process have the appropriate skill sets and opportunities for training to participate meaningfully. These partners include patient, family and caregiver advisors, health system leaders and health care providers.

The Council looks forward to continuing to build and leverage connections with our sector partners, improve access to health care services and enhance patient care and experience. Our central purpose remains unchanged: to ensure the voices of patients, families and caregivers are at the centre of health care system planning.

Appendix **A:**

Self-care and wellness support for Council meetings/consultations

We will acknowledge that these conversations can be triggering!

- Even when we follow our Code of Conduct
- Even though we approach this in a way that recognizes each Council member may have experienced trauma with lasting effects
- Even though we have worked together to create a safe space

We will reaffirm our commitment to each other and invite each other to take care of themselves as they need to throughout the conversation.

- We will offer a quick break if things get heavy
- We will take a moment to honour the space or share with a breath
- We will remind each other to take care of other Council members

We will acknowledge when a conversation may have taken emotional energy and may have affected us.

- We will invite people to take a brief grounding exercise to bring themselves to present
- We will do a "check-out" to move the conversational focus somewhere else (e.g., what is one thing people are taking away and one thing for self-care)
- We will share resources with each other

Appendix **B:**

The Council's Code of Conduct

Guiding principles and core values for the Minister's Patient and Family Advisory Council

As Council members, we will:

- Be guided by the principles and values of respect, collaboration, inclusiveness and innovation
- Contribute to a culture of trust and collaboration, and hold each other in unconditional high regard
- Treat each other with respect, kindness and empathy. Recognize that others' feelings and opinions are valid and worthwhile
- Embody the values of diversity and inclusion. Uphold a safe environment free from stigma, prejudice and discrimination. Demonstrate an attitude that is anti-racist, respectful and inclusive of ability/disability
- Respect each other's time and the boundaries of time within Council meetings
- Share our experiences and learn from others sharing their experiences
- Welcome diverse points of view, understanding that innovation often happens at the intersection of different perspectives. Build upon each other's strengths, embracing others' individuality
- Work to genuinely listen. Be mindful of "sharing the airwaves" to give everyone a chance to contribute
- Value each other's wisdom and honour that by using "I" statements
- Remember that silence is OK and that we all have the right to "pass" if we do not wish to share
- Demonstrate transparency, openness and trust. Foster an environment where members have the freedom to express themselves openly and raise concerns or objections respectfully
- Focus on continuous learning, keeping an open mind and remaining open to learning from each other
- Explore options, share resources and consider various perspectives when there is a decision to make
- Drive original and innovative thinking. Be willing to fail and learn from it
- Honour each member's commitment to the Council. Recognize that we are all valuable members of the team and contribute to the overall learning of the group
- Do our best to attend all sessions and be on time. Be actively engaged and respond to requests in a timely manner
- Be comfortable navigating uncertainty and exercising patience in implementing system-level change
- Demonstrate self-awareness and self-reflection

Appendix **C:**

Council member biographies

Betty-Lou **Kristy** (Chair)

Betty-Lou Kristy 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. For example:

- She has completed three 6-year terms being a board director for Bereaved Families of Ontario Halton-Peel, Canadian Mental Health Association Halton (CMHA-HRB), Halton Alcohol Drug and Gambling Assessment Prevention and Treatment Services (ADAPT), Glen Mills Co-operative Housing Corporation and Addictions & Mental Health Ontario (AMHO).
- She also has training & experience with Children's Aid Society, Big Brothers & Sisters, John Howard Society Youth Restorative Justice, V.O.N Hospice Care/Caregiver programs.
- She has completed the Halton Citizen's Police Academy.

Betty-Lou has received several awards such as the 2009 Centre for Addiction and Mental Health (CAMH) Transforming Lives Award, the 2021-22 Ministry of Health and Long-Term Care (MoHLTC) Achievement, Commitment and Excellence (ACE) 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's Centre for Innovation in Peer Support. The Centre has been awarded the 2017 Ontario Peer Development Initiative (OPDI) Innovators Award, 2017 AMHO President Shield Award and the 2016 Association of General Hospital Psychiatric Services (AGHPS) Celebrating Innovation Award.

Amandeep **Kaur**

Amandeep Kaur is the Chief Operating Officer of the Punjabi Community Health Services (PCHS) based in Brampton. She is passionate about and committed to working with marginalized and diverse populations in her community and beyond, particularly newcomers to Canada.

Her role at PCHS includes leadership, strategic visioning, media relations, fiscal and statistical management, supervision and other management responsibilities. Amandeep has also been active in social work for the last 30 years.

She is the co-founder of the Integrated Holistic Service Delivery Model to address the psycho-social issues in the South Asian community. She has worked with Toronto Public Health and Region of Peel Public Health in community development, health promotion, chronic disease prevention, prenatal care and child health.

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

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 encourages and supports innovation, and looks forward to working 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**

As a veteran of the Royal Canadian Navy, Dean Valentine gained many of his experiences, as well as knowledge and professional competencies, through over 25 years of service to the Canadian Forces (CF). His employment has been in a wide range of working environments both in Canada and abroad.

Due to challenges with a diagnosis of HIV/AIDS in 2008, Dean was released from the CF in April 2014. He found himself challenged to navigate a health care system unfamiliar to him for both physical and mental health conditions. Since his diagnosis, Dean's personal journey, with its successes and challenges, has inspired him to work to build community through engagement with health care initiatives.

Now in career transition, Dean has made Toronto his home and has settled into the community with his husband and daughter. He finds it extremely rewarding to advocate for collaborative people-centred holistic care.

Currently, Dean is a board member of Casey House Hospital, a member of the Downtown East Toronto - Ontario Health Team (DET OHT) Core Group. He is the Chair of the DET OHT Community Advisory Council and Co-Lead of Community Engagement Working Group. He is also an active participant in Ontario Health's Toronto Regional OHT Community of Practice.

Dean continues to support St. Michael's Hospital Academic Family Health Team Patient and Family Advisory Council. In addition, Dean is actively involved in research and engagement projects with the DET OHT, St. Michael's Hospital Mental Health and Addictions, and Casey House Hospital. Focus areas include Community Engagement, Community Reinforcement Approach group therapy, Cognitive Processing Therapy Informed Consent and Harm Reduction models and their impacts on better community health outcomes for vulnerable populations.

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.

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

Joan Duke returned to Thunder Bay after living and working for some time in small-town Northern Ontario. When she was diagnosed with a chronic condition herself and then watched as two families struggled to get their children diagnosed with life-threatening chronic conditions, it became clear to her that patient stories needed to be heard.

Recognizing that the patient/family experience must impact change, Joan volunteered for the Thunder Bay Regional Hospital Patient Advisory Committee. She was subsequently appointed as co-chair of the North West LHIN Patient and Family Advisory Council. She has worked on committees for virtual care, digital health, policy review and quality control and for the Research Institute. As an active volunteer for a diverse group of community organizations, she can listen to and carry back people's experiences and ideas to Ontario's Patient and Family Advisory Council.

Joan finds it gratifying to be part of a system that listens to the patient voice. She is particularly interested in reviewing the COVID-19 response.

Kimberly Cato

Kimberly Cato is a Registered Psychotherapist in Private Practice at True Roots Counselling Services. She identifies as a Queen-Sized Black Woman who engages with the world from a wheelchair. Kimberly has encountered a world of microaggressions, discriminatory practices and subtle or overt acts of racism that caused periods of low self-esteem, social anxiety and battles with body-image issues. Kimberly lives with life-altering chronic pain and an illness that negatively impacts her mobility, but she rises each morning with a heart filled with gratitude and the mindful intention to live life to the fullest.

As a former Ordained Minister and Chaplain in a Toronto community-based hospice, Kimberly is well-versed at making lemonade from lemons. It was this attitude that empowered her during the five years she spent as primary caregiver for both her mother and father who were diagnosed with Alzheimer's Disease.

Kimberly has spent decades working with children in care, at-risk youth in secure treatment, seniors in long-term care, people in palliative care living with life-altering diseases such as HIV/AIDS and cancer, people living with severe mental health issues and people in conflict with the law.

Kimberly leads a weekly support group for Women of Colour called Check-In & Chat and a Monthly Panel Discussion Group called Black Mental Health Experience. She is very familiar with helping people blindsided by life-altering circumstances to transform their trauma into triumph.

Sandi Bell

Sandi Bell is the President of EMPOWWORD Inc, a mediation and training & development firm. She has 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.

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.

Sandi was a school trustee in Hamilton for 12 years and served the education community as an appointed member of Ontario's College of Teachers. She also served as a Member of the Appeal Division of the Immigration & Refugee Board.

She proudly self-identifies as an African-Canadian/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 has held various positions in the banking industry including Administration, Finance, Facilities & Retail Banking as a Personal Banking Representative & Customer Service Manager. She received a liver transplant in 1997 after several years of going undiagnosed with a rare liver disease and Crohn's. After years of treatment for her Crohn's she required a permanent Ostomy in 2012. Sandra has dealt with melanoma and is currently dealing with chronic kidney disease.

Using her lived experience as a transplant patient and as a benefactor of organ donation, she has gone on to advocate for organ and tissue donation. She has also worked to help those afflicted with diseases requiring a transplant and other challenges on their health care journey. Now a co-caregiver for her mom, who has dementia, Sandra has become very interested in the health care system as a whole and how we can improve it with the patient as a partner in their own health care.

Currently, Sandra is working with the Canadian Donation Transplant Research Program as a patient partner co-lead on the Quality of Life Theme. She helps to determine research projects and to design, recruit and assist with knowledge translation. She was on the Steering Committee of the CanRestore Committee, where they implemented several clinical research projects.

Sandra has also been an advisor to Health Quality Ontario. She was recently brought on board as a Patient Advisor at the Health Standards Organization on their Acute and Critical Care Technical Committee. For the past two and a half years, Sandra has served as a Patient Partner on the Muskoka and Area Ontario Health Team Steering Committee. The team was selected as one of the first 24 OHTs.

Sandra has recently joined the Board of PAN (Patient Advisors Network). Locally she volunteers with Gravenhurst Against Poverty and Gravenhurst Women's Centre assisting with their communications and fundraising.

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 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 & President of The Well Community Collective.

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 Conflict Mediation, Violence Prevention, Equity and Anti-Oppression to name a few. 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 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 two, with her own experience related to health and the birthing journey as it relates to health equity and justice.

Sterling **Renzoni**

Sterling is a chemistry and psychology double major 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 experience as a patient in the Ontario health care system, he was able to appreciate its strengths and where there was need for growth. He knows firsthand the pain of battling a debilitating mental illness and fighting to access the appropriate care. After recovering from his eating disorder, Sterling has channelled this pain into passion, becoming an established mental health advocate.

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

Sterling is committed to reshaping 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**

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' 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, 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.

Appendix **D:**

Patient, Family and Caregiver Declaration of Values for Ontario

Accountability	■ We expect open and seamless communication about our care. ■ We expect that everyone on our care team will be accountable and supported to carry out their roles and responsibilities effectively. ■ We expect a health care culture that demonstrates that it values the experiences of patients, families and caregivers, and incorporates this knowledge into policy, planning and decision making. ■ We expect that patient, family and caregiver experiences and outcomes will drive the accountability of the health care system and those who deliver services, programs and care within it. ■ We expect that health care providers will act with integrity by acknowledging their abilities, biases and limitations. ■ We expect health care providers to comply with their professional responsibilities and to deliver safe care.
Empathy & Compassion	■ We expect that health care providers will act with empathy, kindness and compassion. ■ We expect individualized care plans that acknowledge our unique physical, mental, emotional, cultural and spiritual needs. ■ We expect that we will be treated in a manner free from stigma, assumptions, bias and blame. ■ We expect health care system providers and leaders will understand that their words, actions and decisions strongly impact the lives of patients, families and caregivers.
Equity & Engagement	■ We expect equal and fair access to the health care system and services for all regardless of ability, race, ethnicity, language, background, place of origin, gender identity, sexual orientation, age, religion, socioeconomic status, education or location within Ontario. We further expect equal and fair access to health care services for people with disabilities and those who have historically faced stigmatization. ■ We expect that we will have opportunities to be included in health care policy development and program design at local, regional and provincial levels of the health care system. ■ We expect an awareness of and efforts to eliminate systemic racism and discrimination, including identification and removal of systemic barriers that contribute to inequitable health care outcomes (with particular attention to those most adversely impacted by systemic racism).
Respect & Dignity	■ We expect that our individual identity, beliefs, history, culture and ability will be respected in our care. ■ We expect health care providers will introduce themselves and identify their role in our care. ■ We expect that we will be recognized as part of the care team, to be fully informed about our condition, and have the right to make choices in our care. ■ We expect that patients, families and caregivers be treated with respect and considered valuable partners on the care team. ■ We expect that our personal health information belongs to us, and that it remain private, respected and protected.
Transparency	■ We expect that we will be proactively and meaningfully involved in conversations about our care, considering options for our care and decisions about our care. ■ We expect that our health records will be accurate, complete, available and accessible across the provincial health system at our request. ■ We expect a transparent, clear and fair process to express a complaint, concern or compliment about our care that does not impact the quality of the care we receive.

Updated: July 2021 **Note:** The purpose of this Patient Declaration of Values, drafted by the Minister's Patient and Family Advisory Council in consultation with Ontarians, is to articulate patient, family and caregiver expectations of Ontario's health care system. The Declaration is intended to serve as a compass for the individuals and organizations who are involved in health care and reflects a summary of the principles and values that patients, families and caregivers say are important to them. The Declaration is not intended to establish, alter or affect any legal rights or obligations, and must be interpreted in a manner that is consistent with applicable law.

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