



# Patient, Family & Public Advisors Council

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OUR FIRST YEAR IN REVIEW  
(September 2015 to August 2016)

**Health Quality  
Ontario**

*Let's make our health system healthier*





# Message from Health Quality Ontario's Patient Family and Public Advisors Council Co-Chairs

At the time of writing this, it's been a little over a year since Health Quality Ontario's Patient, Family and Public Advisors Council came together. From beginning with the orientation weekend through to today, we have learned not only who Health Quality Ontario is and what is expected from us, but more importantly, have started to make a difference.

As you will read, we have participated in dialogues on a wide variety of health quality issues. We also visited health care organizations and met with service providers to learn more about their work and how our input can have an impact on the quality of care for the people of Ontario. This report is a reflection from the members of Health Quality Ontario's Patient, Family, and Public Advisors Council. You're learning about the Council from the members themselves - our work, learning and reflections are broken down meeting-by-meeting.

Most of our members joined with a lot of enthusiasm, but some had initial reservations. For some, sharing their personal health story with others, and working as a patient advisor was a new experience. Other members had experience as Patient Advisors, and felt more comfortable from the very beginning. This created a great dynamic between members where we challenged one another to bring out the best in each other and our Health Quality Ontario partners.

We set clear expectations and worked diligently with the Health Quality Ontario senior leadership team and Board of Directors to ensure the goals and expectations of the organization resonated with ours. After this first year of working together, in our opinion, we have exceeded all expectations. We feel empowered; our enthusiasm has been justified; and we feel an even deeper commitment

to Health Quality Ontario and its mandate to improve the quality of care for all people living in Ontario.

As we move forward, we will increase our membership to 24, its diversity, and the number of full-day meetings within the year to six as we continue to advise on a number of strategic priorities. Our Advisors Council responsibilities have only just begun.

It has been a pleasure and privilege to act as Co-Chairs to Health Quality Ontario's Patient, Family and Public Advisors Council and we look forward to further opportunities to improve health care quality for Ontarians.

*\* Our use of the word 'patients' represents all who are served by our health system – in hospitals, in long-term care homes, in community programs and in their own homes.*

*\* Our use if the word 'family' represents all caregivers as identified by the patient.*



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# Message from Dr. Joshua Tepper

## President and CEO, Health Quality Ontario

Truly engaging patients to build a better health care system is one of the guiding principles behind the work of Health Quality Ontario and a principle to which I have made a strong personal commitment.

As such, it gives me great pleasure to introduce this first report of the Health Quality Ontario Patient, Family and Public Advisors Council – the Council being one of the focal points of our strategy to foster a collaborative and empathetic culture in our health care system through patient engagement.

We engage patients at Health Quality Ontario in many different ways. When we set out to establish the Advisors Council, we took time to focus on the role and purpose of such a council and how it could make a meaningful contribution to our existing programs.

Interest in participating in the Council was gratifying and there were many applications from people wishing to be involved. In their first year of activity, the passion and commitment shown by members of the Council has been inspirational. Members have contributed to

an impressive number of initiatives as they provided input on how to advance projects in a way that reflects patient and caregiver needs, values, and goals.

As a result of its first four meetings detailed in this report, the Council has made significant contributions to the work of Health Quality Ontario while also providing an opportunity for council members to network and engage in discussions with each other and with staff outside of council meetings to help strengthen their role.

The work and influence of the Council is only going to grow.

In the coming year, there are plans to increase membership of the Council to its full complement of 24, to add more diversification to its membership, and to increase the number of meeting times up to six, as they continue to advise Health Quality Ontario on a number of key programs and patient engagement activities. I look forward to working closely with this larger Council as the membership continues to personify the central role held by patients and family in contributing to health care improvements in our province.

I also want to extend a personal thank you to each individual member for their energy, contribution, and for the time they give. Their dedication and enthusiasm for the work inspires us all.

## Introduction to the Council

# How We Got Involved

In September 2015, Health Quality Ontario began a journey to embed the lived experience of patients, families, and the public into all of its work, and invited patients like us to get involved. The organization knew engagement would ensure its efforts to improve health care quality were meaningful and relevant to the users of Ontario's health system. Central to these engagement efforts has been the creation of a Patient, Family, and Public Advisors Council.

We as Council members all learned about the opportunity to get involved in different ways. Promotion of the expression of interest was communicated in many ways, including Health Quality Ontario's website, through their partner organizations, and social media. President and CEO, Dr. Joshua Tepper was even featured in a video, asking for people to get involved as well.

Over 160 expressions of interest forms were received and reviewed by Health Quality Ontario's Patient Engagement team. After extensive interviews and internal discussions, the first 16-members were selected, representing individuals from across the province with varying ages, backgrounds and health care experiences.

Through our insights and lived experience, it is the job of the Council to ground the work of Health Quality Ontario, ensuring what matters to those who lie at the heart of our health care system - patients, families, and members of the public – guides and remains a priority for the organization.



“We were actively seeking to engage with people from across the province, people with experience in advising and new to the role of Patient Advisor. We wanted people with varied level of knowledge of the health system, and a diversity in age, gender and health experiences.”

— *Health Quality Ontario Team Member*

# Members

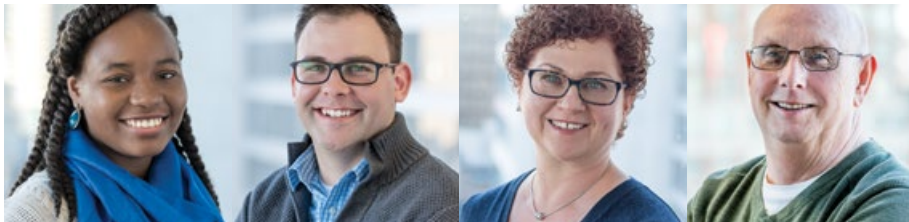


Lucie Allard

Donna Brown-Bowers

Samira Chandani

David Chilton



Adellah Chimbindi

John Dabous

Marisa Granieri

Bill Holling



Michael Low

Claude Lurette  
(Co-chair)

Lynda McArthur

Sara Shearkhani



Gideon Sheps

Gene Szabo

Kowsiya  
Vijayarathnam  
(Co-chair)

Calvin Young



## Members Reside In:

- 10 of 14 LHINs
- Small towns or cities (1,000 to 100,000) (12.5%)
- Mid-sized cities (100,000 – 1,000,000) (43.75%)
- Large urban centres (over 1,000,000) (43.75%)



## Ethnic & Cultural Diversity:

- 37.5% of members are foreign born
- 25% self-identify as a racialized minority
- 18% primarily speak languages other than English at home



## Varied Health Care Experiences



## Education:

- Secondary high school diploma/equivalent (12.5%)
- Postsecondary qualification (37.5%)
- Graduate or professional education (50%)



## Age Breakdown:

- 18-35 years (18.75%)
- 36-55 years (31.25%)
- 56-64 years (18.75%)
- 65-80 years (31.25%)

# Council Demographics



In this video, Council Members describe why we chose to get involved with Health Quality Ontario to improve the quality of care across the province.

For more from the Council, visit the Video Stories and Reflections page on the Health Quality Ontario website:  
[HQOntario.ca/Engaging-Patients/Video-Stories-and-Reflections](https://www.hqontario.ca/Engaging-Patients/Video-Stories-and-Reflections)



This is an example of the promotional material the team at Health Quality Ontario used to help spread the word about the Council and the call for expressions of interest.

**Health Quality Ontario is always looking for more patient, family and public advisors to help inform the work they do.**

For more information on how to get involved, visit:  
[HQOntario.ca/engage](https://www.hqontario.ca/engage)

# Overall Achievements

## Governance

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- Developed Terms of Reference for our Council focused on goal-setting and evaluation, membership, roles and responsibilities, and recommendations and reporting
- Determined Co-chairs
- Determined Co-chair selection process
- Set the governance foundation for future Councils and our success

## Learnings and Site Visits

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- Role, mission, mandate of Health Quality Ontario
- Health Quality Ontario's strategic plan, areas of focus, and business plan
- Quality improvement
- Health system reporting
- Sumac Creek Health Centre
- Toronto Birth Centre
- Building Roads Together
- Thunder Bay Regional Health Science Centre
- Northern Ontario School of Medicine
- Anishnawbe Mushkiki Aboriginal Community Health Centre
- Réseau du mieux-être francophone du Nord de l'Ontario

## Feedback on Health Quality Ontario Projects

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- Quality Improvement Plan indicators and priority areas
- How to enhance health system performance public reporting
- Health Quality Ontario's response to the Minister of Health and Long-Term Care's *Patients First* Paper
- A report to the Minister of Health and Long-Term Care for an Ontario approach for patient engagement, including a patient engagement framework for the province
- The development of patient engagement tools and resources to help patients and professionals build their capacity to effectively engage with each other

## Engagement Opportunities Beyond Council Meetings

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- Recruiting patient advisors for an Health Quality Ontario advisory committee of patients and professionals dedicated to developing patient engagement learning tools
- The selection process for the Minister's Medal on Health Quality and Patient Safety
- Participation on an Advisory Committee contributing to the development of the Health Quality Ontario health equity plan
- Input into a Patient and Public Engagement Evaluation Tool Implementation Study
- Input into a special report by Health Quality Ontario on quality of health care in Ontario's north
- Co-Designing breakout sessions for Health Quality Ontario's 2016 annual conference (Health Quality Transformation)

ENCOURAGE  
COLLABORATION TO  
ACHIEVE SOLUTIONS

# Building Our Foundation

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***1<sup>st</sup> Advisors Council Meeting***  
Toronto, Ontario (October 2015)

## **AGENDA**

- Welcome and Introductions
- Patient Storytelling and Team-Building
- Orientation to Health Quality Ontario
- Site Visits
- Council Business







“We felt the trust building between the organization and our group – this is huge, particularly in health care contexts.”

– Council Member

## Highlights of the Meeting

**PATIENT STORYTELLING:** Team-building to learn about each other and the wealth of experiences we each bring to the Council.

**SITE VISITS:** Seeing the health care system in action allowed for reflection on people’s experiences with the various sectors of care.

**COUNCIL BUSINESS:** Reviewing and discussing a draft Terms of Reference, Participation Agreement, and Code of Conduct to ensure Council functioning and sustainability.



“Initially, I came to Toronto feeling like ‘what can I contribute to the group’? [The orientation meeting] was an eye-opener and I left feeling so much better.”

– Council Member





# Rolling Up Our Sleeves

*2<sup>nd</sup> Advisors Council Meeting*  
Toronto, Ontario (January 2016)

## **AGENDA**

- Overview of Health Quality Ontario's Strategic Plan
- Report on Patient Engagement for the Minister of Health and Long Term Care
- Health Quality Ontario's Public Reporting Program
- Council Business



“Working with the Council has brought new perspectives to our reporting. We always have fruitful discussions that lead us to look at things from a different angle, which adds depth and richness to our reports. Most recently we’ve engaged with a Council member to help develop how to regularly connect with them online, so we can engage more of the Council members on a regular basis.”

– Health Quality Ontario Team Member

## Highlights of the Meeting

### **PATIENT ENGAGEMENT ACROSS THE PROVINCE:**

Identifying what it takes for patients to become partners towards improving health care quality.

**REPORTING ON OUR HEALTH SYSTEM:** Determining what is important to patients in order to ensure Health Quality Ontario reports are rooted in patient experiences.

**COUNCIL BUSINESS:** Getting deeper into how the Council will function.



“My biggest learning was during the sub-group work for the Terms of Reference. At first, I thought there was too much focus on this, but in the end, I thought it was really important to understand who we are and what our purpose is. I thought it was a great value. I realized that if we don’t do that, we won’t be able to come together.”

– Council Member



# Focusing on a Key Program

*3<sup>rd</sup> Advisors Council Meeting*  
Toronto, Ontario (April 2016)

## **AGENDA**

- Health Quality Ontario's Quality Improvement Plan program
- Follow up on Public Reporting
- Update on Sub-Committee Work
- Council Business





“The meeting was structured well, I liked that there were different groups focusing on different topics. I felt really engaged and that it was really useful to learn the whole process of what goes on in shaping a Quality Improvement Plan.”

– Council Member

## Highlights of the Meeting

**PLANNING FOR QUALITY IMPROVEMENT PLANS:** Going in-depth to identify new issues and topics for Quality Improvement Plan indicators to drive quality improvements.

**FEEDBACK ON COUNCIL INPUT ON PUBLIC REPORTING:** Hearing how Council input helped to evolve Health Quality Ontario’s approach towards public reporting.

**COUNCIL BUSINESS:** Finalizing key elements of the draft Terms of Reference.



“What we heard was extremely useful in helping to shape the final 2017-18 Quality Improvement Plan indicators, to ensure the patient lens is adequately represented.”

– Staff Member





# Learning About Health Care and Engagement in Northwestern Ontario

**4<sup>th</sup> Advisors Council Meeting**  
Thunder Bay, Ontario (June 2016)

## **AGENDA**

- Site Visits and Presentations
- Meeting Other Patient Advisors
- Developing Resources
- Council Business



“I don’t want to sound too dramatic here but something magical happened in Thunder Bay. We left there as a real council and a group of friends that guaranteed success for us in the future.”

– Council Member

## Highlights of the Meeting

### LEARNING ABOUT EXPERIENCES IN NORTHWESTERN ONTARIO:

Understanding the unique health care parameters, barriers, and solutions in the area.

### BUILDING RELATIONSHIPS WITH OTHER PATIENT ADVISORS:

Hearing about some of the needs of advisors who work in other parts of the health system.

**HEALTH EQUITY:** Hearing about others’ lived experience and what it means to live in an underserved population.

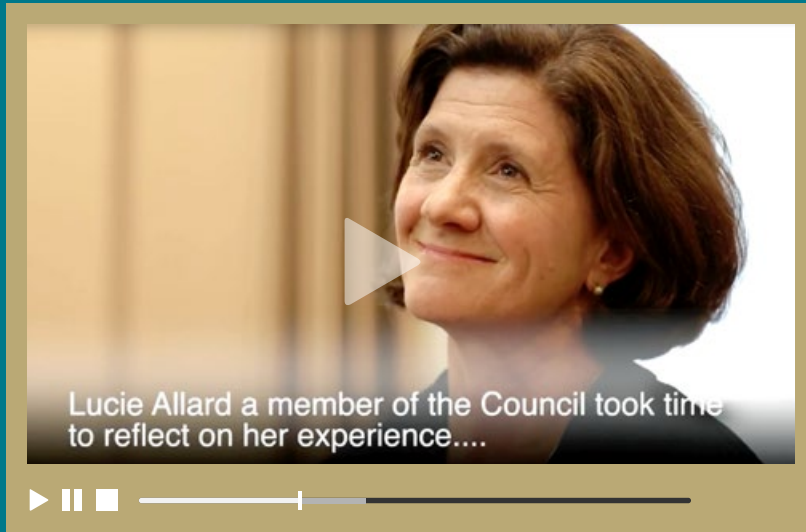


## Organizations Visited

An important part of the weekend involved meeting with various organizations and patient advisors from the area. We wanted to hear not only from those who deliver care and work in patient engagement, but also from those who participate as patients and bring their own insights from their lived experience.

The site visits and conversations we had truly helped us better understand how unique health care delivery methods, challenges and approaches can be across the province.





Lucie Allard, a member of the Council shares her thoughts and reflections on the Council meeting held in Northwestern Ontario and the health care system in the region.

For more from the Council, visit the Video Stories and Reflections page on the Health Quality Ontario website:  
[HQOntario.ca/Engaging-Patients/Video-Stories-and-Reflections](https://www.hqontario.ca/Engaging-Patients/Video-Stories-and-Reflections)

“At this meeting, the Council really solidified their relationship as a team and as a partner to Health Quality Ontario. I witnessed an excitement and an energy from the Council members that will support ongoing inspiration for the difficult (and important) work ahead.”

— Health Quality Ontario Team Member



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# Reflections on the First Year of the Patient, Family, and Public Advisors Council

What a great journey this first year has been! Despite only meeting four times, so much was accomplished. The Council has gone from a collection of 16 strangers to a connected group of peers working hand-in-hand to help to guide and ground Health Quality Ontario.

This journey has sparked growth for everyone involved. We have learned about Health Quality Ontario, our health system, and the ways in which we can improve the quality of care for people across the province.

The team at Health Quality Ontario have similarly grown, with greater interest and willingness across the organization to seek out opportunities for feedback from the Council. As a result, new items for discussion are continually coming forward with the aim of deep, ongoing, and meaningful conversation rooted in what matters as a patient.

While much has been achieved in the first year of the Council, many steps have been identified towards even greater growth and learning together, because we know that better has no limit.

With enthusiasm for the year to come,

*The Patient, Family and Public Advisors Council  
of Health Quality Ontario*



In this video, some of us took the time to reflect and look back on our first year working with the Health Quality Ontario on the Council.



Members of the Patient Engagement team at Health Quality Ontario also took some time to reflect and look back on the work done so far, and why the Council has been so important to the organization.



# Links to Resources

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The Council in partnership with the Patient Engagement team at Health Quality Ontario developed tools, resources and documentation that may be useful to other Patient and Family Advisory Councils. They are linked below.

1. [\*Sample Agenda\*](#)
2. [\*Terms of Reference\*](#)
3. [\*Code of Conduct\*](#)
4. [\*Participation Agreement\*](#)

For more, visit Health Quality Ontario's [\*\*\*Patient Engagement Tools and Resources Hub\*\*\*](#).

Working with patients, families and health providers, Health Quality Ontario gathers and develops tools and resources to support their engagement efforts.

If you have questions or resources you would like included in the hub, please contact: [\*\*\*engagement@hqontario.ca\*\*\*](mailto:engagement@hqontario.ca)



# What Is Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

## Who We Are

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

## What We Do

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voice of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

## Why It Matters

We recognize that, as a system, we have much to be proud of, but also that it often falls short of being the best it can be. Plus certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

# Health Quality Ontario

*Let's make our health system healthier*

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