



International Foundation  
for Integrated Care  
*IFIC Canada*

HSPN



Health System  
Performance  
Network



# The relationship between patient and caregiver engagement and integrated care

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October 24<sup>th</sup> 2023 from 12:00 – 1:30 PM EST



International Foundation  
for Integrated Care  
*IFIC Canada*

## IFIC Canada Co-Founders



**Jodeme Goldhar**  
*@JodemeGoldhar*



**Walter Wodchis**  
*@WWodchis*

## Today's Co-Host



**Kerry Kuluski**  
*@Dr\_KerryK*

# WELCOME!

## *How to Take Part in the Virtual Community*

Please use the **chat box** to **introduce yourselves**, **ask questions** and **contribute** throughout the session.



Share your thoughts on social media using the hashtags:

**#IFICCanada**



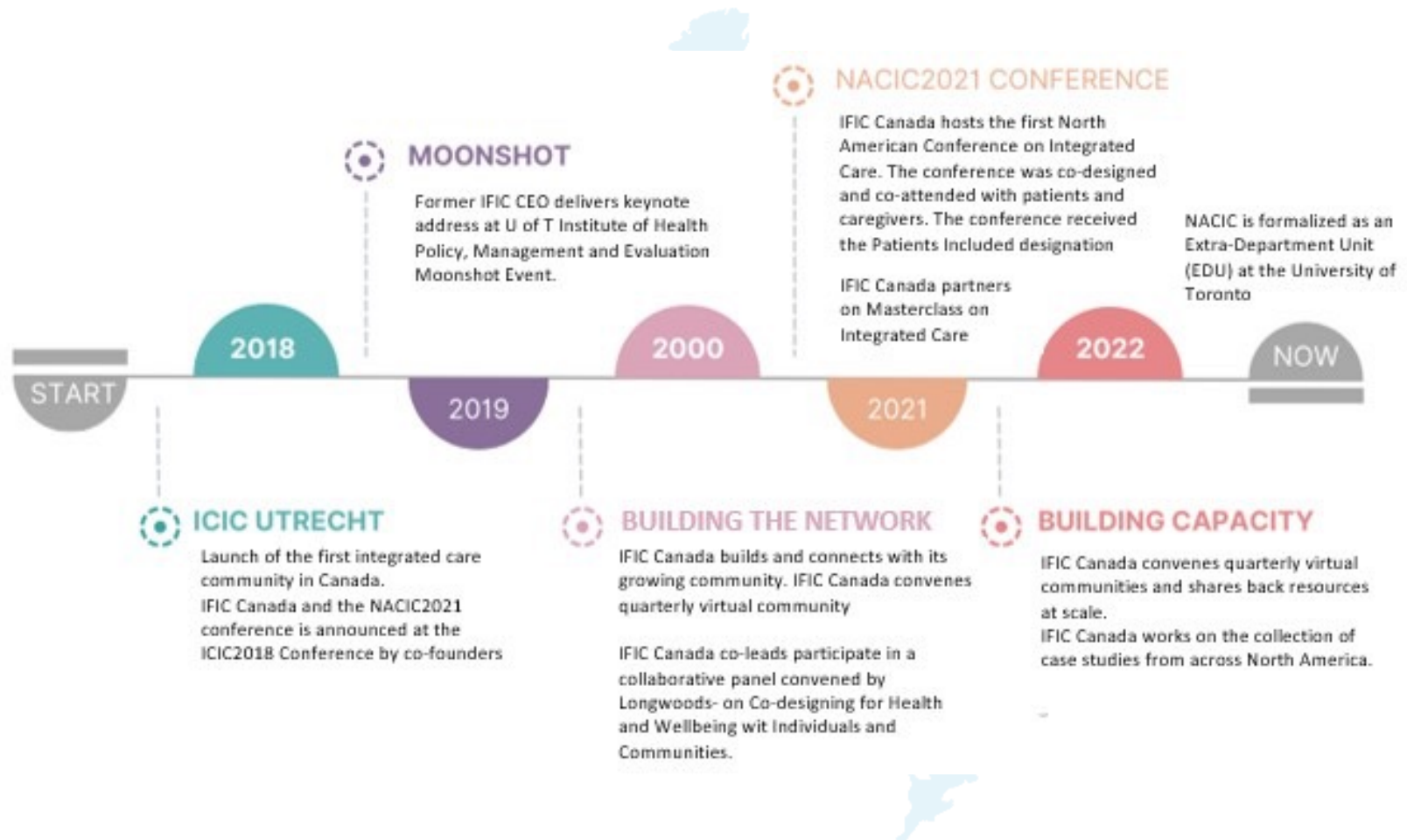
Please send chat messages to **all participants and attendees** so everyone can see. If you are replying in the chat box to someone else, please start your comment with **@[theirname]**

# Where Are You Joining Us From?

Let us know via the chat box



# IFIC Canada Journey



# Land Acknowledgement

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We acknowledge the land on which we are hosting this meeting is the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. We also acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit.

We acknowledge that Canada is home to many diverse First Nations, Inuit and Métis peoples, and that each of you are joining us from one of those many traditional and treaty territories.

We are grateful to be able to come together in this way.

# Poll 1: We'd Like to Know...

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Is this your first time joining the virtual community?

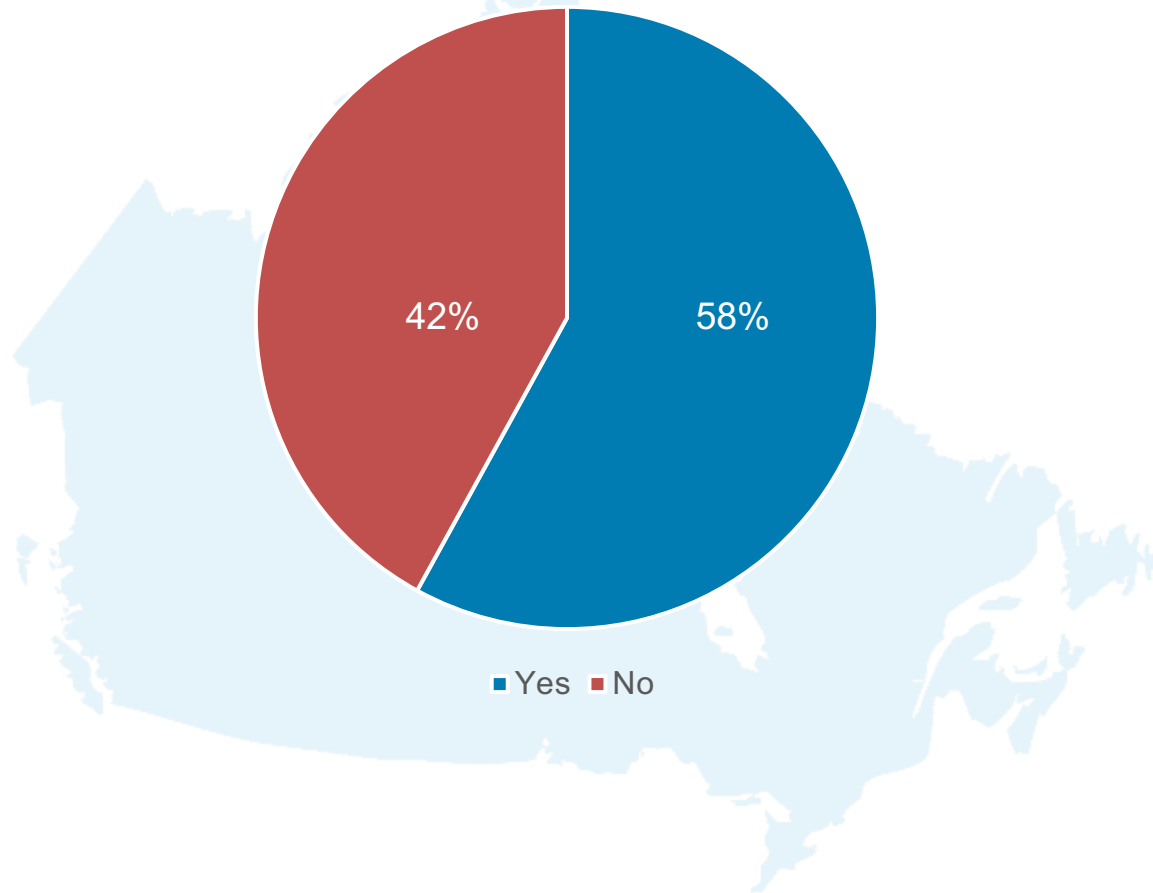
Yes

No

# Example Poll Results: We'd Like to Know...

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Is This Your First Time Joining The Virtual Community



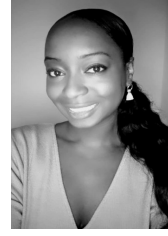


# Making It All Happen

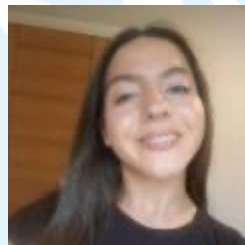
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**Trisha Martin**



**Yinka Macaulay**



**Niamh Daly Day**



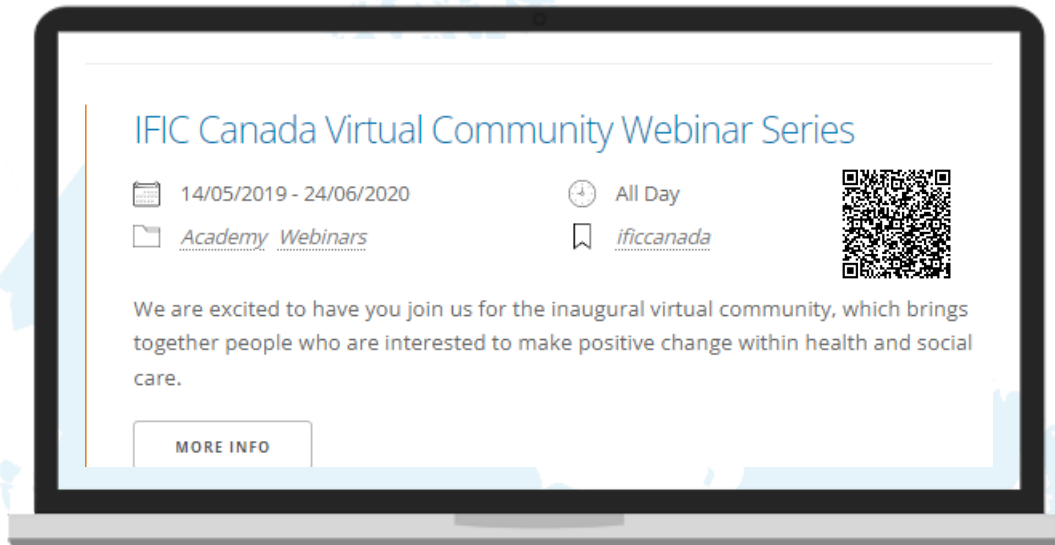
**Fiona Lyne**  
*@spiderslips*



**Miriam Galvin**

# Previous Sessions

You can find **ALL** of our previous sessions at <https://integratedcarefoundation.org/events/ific-canada-virtual-community-webinar-series>



intrigued inspired excited  
relevant elementary positive  
determined **hopeful** connective  
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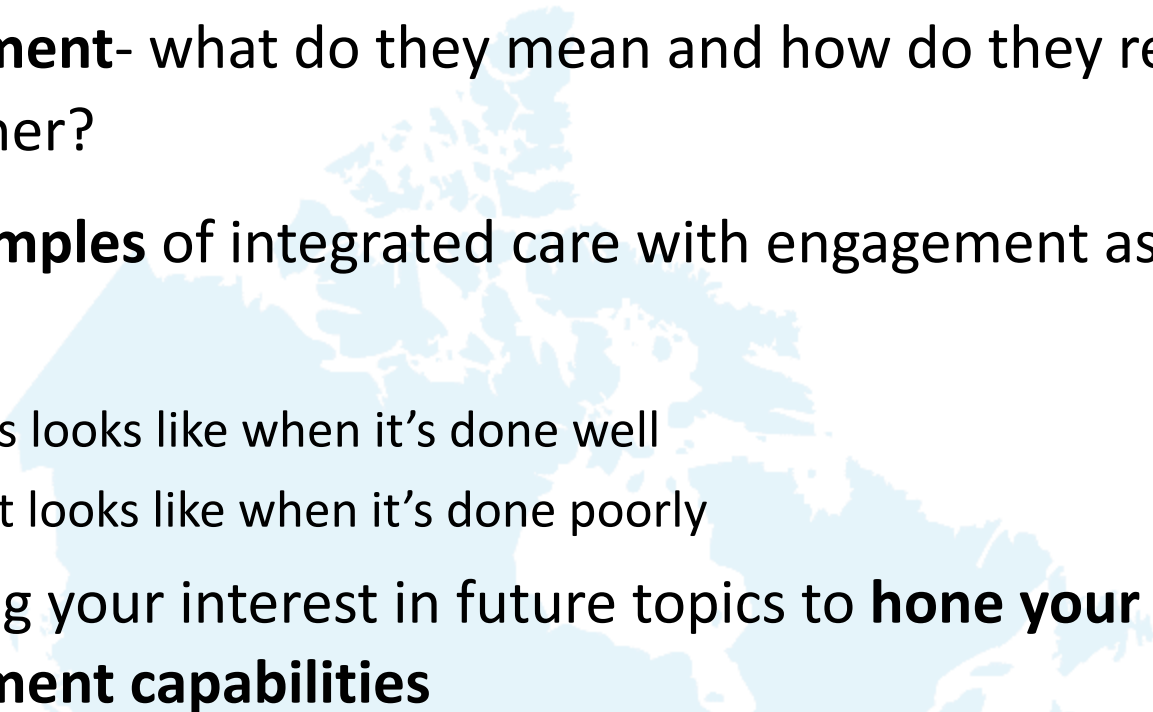
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# Today's Topics

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- 1. Integrated Care and Patient/Caregiver/Community Engagement**- what do they mean and how do they relate to each other?
  - 2. Key examples** of integrated care with engagement as a core focus
    1. What it looks like when it's done well
    2. What it looks like when it's done poorly
  - 3. Assessing your interest in future topics to hone your engagement capabilities**
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# Meet Today's Speakers!

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**Helen Lightfoot**  
Senior Practice Consultant  
with Connecting People and  
Community for Living Well,  
an Alberta Health Services  
initiative



**Sandra Holdsworth**  
Patient Partner,  
PAN



**Robin Miller**  
Joint Editor in Chief of the  
International Journal of Integrated  
Care and a Senior Fellow of the  
School for Social Care Research



**Nakia Lee-Foon**  
Inaugural Health Equity Lead at the  
Institute for Better Health (IBH), at  
Trillium Health Partners



**Kerry Kuluski**  
Inaugural Dr. Mathias Gysler Research  
Chair in Patient & Family Experience and  
Scientist, IBH; Associate Professor, IHPME

# Integrated Care

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What do we mean?

## A social science/health system perspective

“A coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create **connectivity, alignment and collaboration** within and between the **cure** and care sectors. The goal is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings.” Contandriopoulos et al 2014

## A patient perspective

“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.” Lewis et al 2010

Cited in Goodwin 2016

# Patient and caregiver engagement

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What do we mean?

“Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.”

Carman et al (2013, p.224)

# Patient and caregiver engagement

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## Degrees of engagement and sharing of power



**Era One:  
Sharing Information**

**Power differential  
between provider(s),  
patients and  
caregivers**



**Era Two: Engaging  
Patients and their  
Families**

**Shifting power  
differential between  
provider(s), patients  
and caregivers**



**Era Three:  
Co-Define and Co-  
Design**

**Power is shared  
between provider(s),  
patients and  
caregivers**

# Engagement is required if we want to have collective impact

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**“An intentional way of working together and sharing information for the purpose of solving a complex problem.”**

- National Council of Nonprofits



**“The complex nature of most social problems belies the idea that any single program or organization, however well managed and funded, can singlehandedly create lasting large scale change.”**

-Fay Hanleybrown, John Kania, & Mark Kramer



Collaboration

# The Relational Work of Systems Change

Collective impact efforts must prioritize working together in more relational ways to find systemic solutions to social problems.

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CITE SHARE COMMENT PRINT ORDER REPRINTS

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By Katherine Milligan, Juanita Zerda & John Kania | Jan. 18, 2022

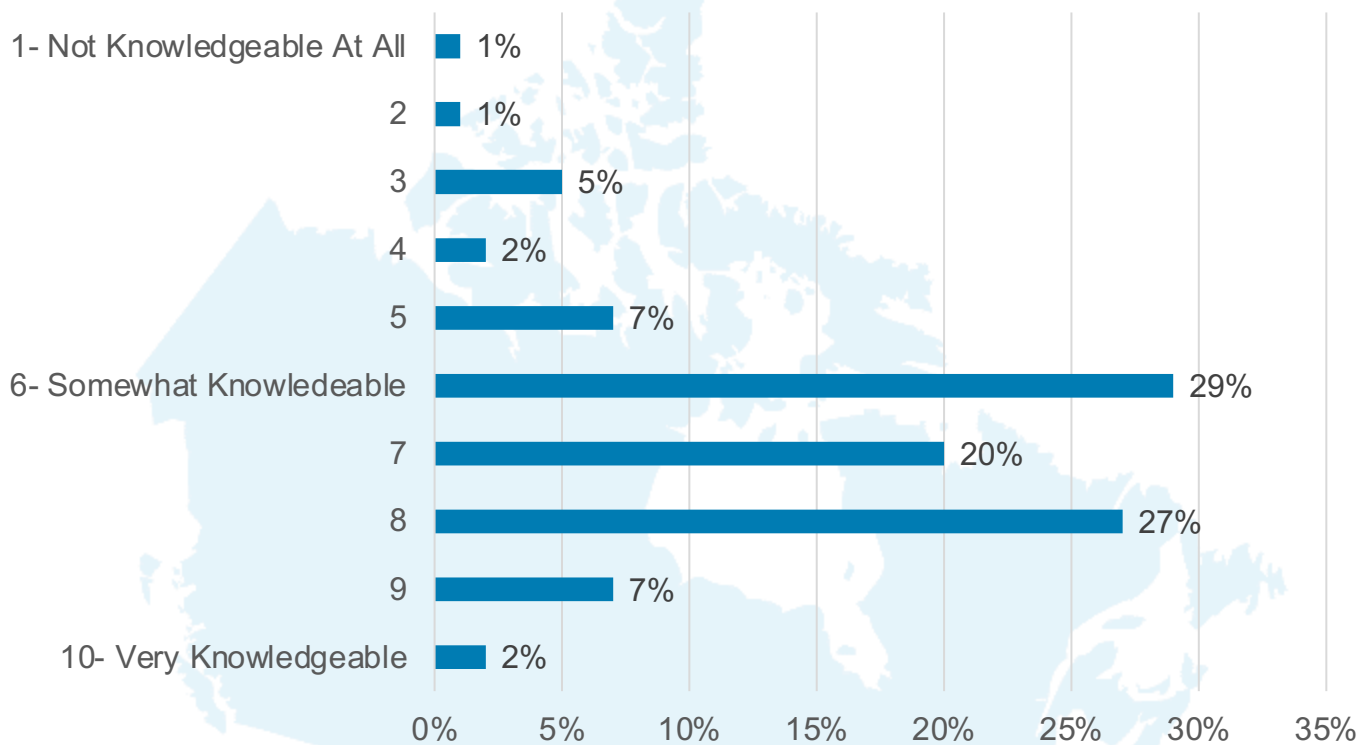


(Illustration by Hugo Herrera)

“Relationships are the essence and fabric of collective impact. What’s critical for those who facilitate collective impact efforts is to **support relationship development** in ways that **build true empathy and compassion** so that **authentic connections** happen, particularly **between diverse participants**. These deeper connections can form new avenues for innovation to address the social problem at hand.” Katherine Milligan and colleagues

# Poll Results: Your Knowledge About Today's Topic

How knowledgeable are you about patient caregiver engagement and integrated care?



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# Key Excerpts From Discussion



# Voices from the Virtual Community

## Engagement, Partnership and Co-design

And it's really about people... Coming together, whether you're a patient, a family member, a friend, neighbor or professional in active partnership. This could be in a clinical encounter or at an organizational level where you're doing co-design work, planning something together, governance [or working] at policy making level, ultimately with the goal of improving health and healthcare. Pulling together a collective expertise to make things work better.

-Kerry Kuluski

“It shouldn't be a nice to have. It should be something that we should see as a requirement of strong professional practice”

– Robin Miller

“We should be actively engaging and having conversations with caregivers, patients, and community members from the very beginning.”

– Nakia Lee Foon

# Reflections from the Virtual Community

## Building skills and capabilities

“The other thing I think we need to think about is giving people the skills and the confidence to to meaningfully involve people in their practice and their research. I think there's a big role for professional bodies regulators to make sure that throughout people's professional career, right from the time that qualifying through post, qualifying in terms of their performance, appraisal development, that we have the skills and the knowledge of how to engage people”  
-Robin Miller

“Codesign is not pretty, as it can get messy, but messy will open up doors to understand the social challenges...see things from my world as a PFA ”  
– Pamela Barkhouse

“We need to work towards changing the provider patient differential, by having providers see their patients as partners [and] through shared decision-making”  
– Sandra Holdsworth

# Voices from the Virtual Community

## Improvement and Impact

“I think it's really important that we show impact in lots of different ways. I think the stories from the people who are involved. And then the stories from the people who are impacted”

– Helen Lightfoot

“Certainly, we have evidence that involving people does make a difference in the design, it makes the care model more valuable.”

– Walter Wodchis

“Although we brought up things that are not working, and we're addressing... there's a lot of things that are working. [And] the people here that are on this call are dedicated.”

– Sandra Holdsworth

“We need to measure how our organizations are doing patient engagement. What what involvement does a community have? What voices does the patient have and stuff like that.

And we also have to remember unfortunately, our healthcare system was not built for the end users... Bringing patients, families in the community to the table we can restructure.”

- Sandra Holdsworth

# Voices from the Virtual Community

## Equity lens within engagement

“How we're defining equity in the context of where we work is beyond importance to to start that journey. To better engage for integrated care.”

-Nakia Lee Foon

“And of course there's also different degrees of engagement. And with these different degrees, there's different levels of power.

When we talk about engagement, we're talking about power. And clearly, there's some groups that historically have a lot more power in these types of interactions than others.”

-Kerry Kuluski

“One of the things that that I see all the time is that we're very much a referral based system. And that's around power and gatekeeping ... If we can move away from that and make it a partnership, so we are talking about what's needed and everybody's at the table.

-Helen Lightfoot

“Experience is an expertise, and it should be treated as such, and it should be compensated fairly”

– Nakia Lee Foon

# Resources shared in the Chat

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- Several references and resources were shared during the discussion. These are listed here organized by topic area.





# Resources

## Community Health and Wellbeing

News and media - Recent stories that are relevant to the Tasman Peninsula:

<https://tasmanconnect.org.au/our-stories/>

## Patient and Community Engagement

McMaster's Public and Patient Engagement Collaborative: <https://ppe.mcmaster.ca/>

Co-production (UK): <https://www.scie.org.uk/co-production>

Builder, Expert, Disruptor, Leader: The Many Roles of People with Lived Experience, Miller et al. (2023) : <https://pubmed.ncbi.nlm.nih.gov/37637213/>

Public and patient involvement in research (Ireland):

<https://www.hrb.ie/funding/funding-schemes/public-and-patient-involvement-in-research/>

# Resources

## Playbooks and Roadmaps

Greater Hamilton Health Network Playbook WOMEN'S HEALTH DAYS:

<https://greaterhamiltonhealthnetwork.ca/wp-content/uploads/2022/05/WHD-Playbook.pdf>

Better Together: The Health Services Patient Engagement Roadmap (Ireland)

<https://www.hse.ie/eng/about/who/national-services/partnering-with-patients/resourcesqid/hse-better-together-patient-engagement-roadmap-book.pdf>

PPI Ignite Network Values and Principles Framework: <https://ppinetwork.ie/resource/ppi-ignite-network-values-and-principles-framework/>

## Governance

Inconsistent Governance Structures for Health and Social Services Limit Service

Integration for Patients with Complex Care Needs:

<https://www.longwoods.com/content/27180/healthcare-policy/inconsistent-governance-structures-for-health-and-social-services-limit-service-integration-for-pati>

# Resources

## Leadership

CITIZEN LEADERSHIP: CO-CREATING INTEGRATED CARE :

[https://warwick.ac.uk/fac/sci/med/about/centres/arc-wm/news-events/citizen\\_leadership\\_and\\_integrated\\_care\\_report\\_accessible\\_pdf\\_may\\_2023.pdf](https://warwick.ac.uk/fac/sci/med/about/centres/arc-wm/news-events/citizen_leadership_and_integrated_care_report_accessible_pdf_may_2023.pdf)

## Primary Care

Modernizing Alberta's primary health care system (MAPS) - Strategic Advisory Panel final report: <https://open.alberta.ca/publications/maps-strategic-advisory-panel-final-report>

Do People with Disabilities Have Difficulty Finding a Family Physician? By McColl et al. (2015) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4454931/>

## Caregivers

Giving Care: An approach to a better caregiving landscape in Canada :

[https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE\\_Giving-Care.pdf](https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf)

Caregivers as Partners eLearning for Healthcare Providers:

<https://ontariocaregiver.ca/caregivers-as-partners-elearning-for-healthcare-providers/>

# Resources

## **Social Determinants of Health**

Women Experiencing Homelessness, Women's Health Drop-In Days:

<https://greaterhamiltonhealthnetwork.ca/2021/08/23/being-adult-allies-to-a-courageous-generation-5/>

Dr. Andrew Boozary prescribes housing to curb homelessness:

[https://www.uhn.ca/corporate/News/UHN\\_Podcasts/Behind\\_the\\_Breakthrough/Pages/season5-episode1-andrew-boozary.aspx](https://www.uhn.ca/corporate/News/UHN_Podcasts/Behind_the_Breakthrough/Pages/season5-episode1-andrew-boozary.aspx)

## Poll 3: What do you want to learn about more...Rank the following topics (with 1 being the topic you would most like to see in a future webinar and 7 the least)

75/75 (100%) answered

A. Communication, compassion and empathy 75/75 100%



B. Bearing witness to lived experience (learning how to share and receive patient/caregiver stories) 75/75 100%



C. Equity, diversity and inclusion 75/75 100%



D. Navigating difficult conversations 74/75 99%



E. Preparing for engagement activities 73/75 97%



F. Conducting engagement activities (including real time practice simulation) 74/75 99%



G. Evaluation of engagement activities 74/75 99%

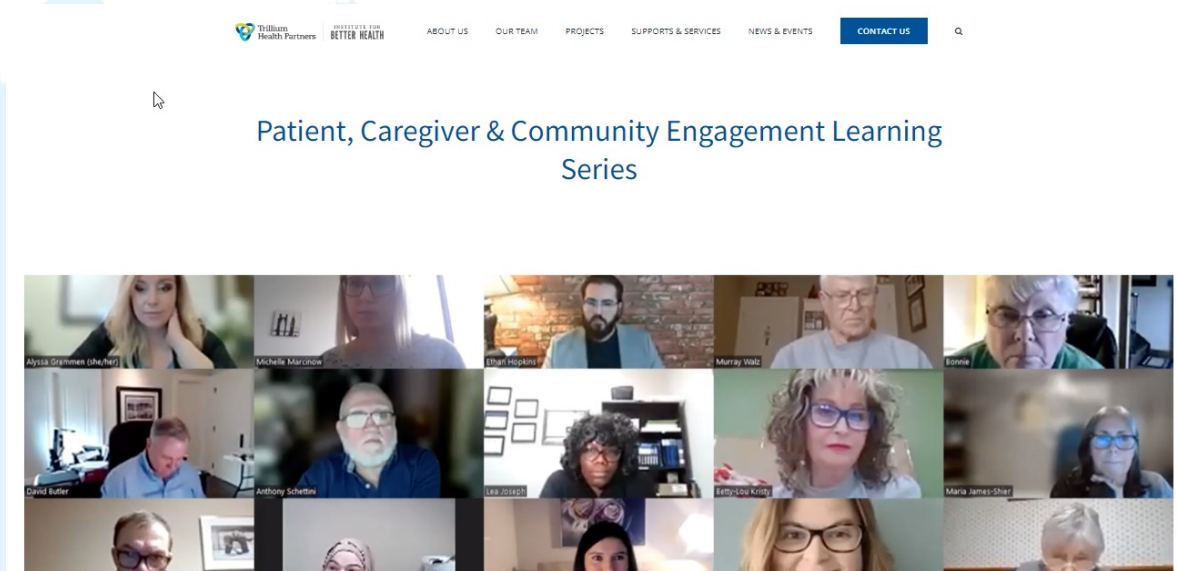


1 - topic you would mo... 2 3 4 5 6 7 - topic you would leas...

# Check out our Engagement Series Learning Library!

7 in-depth engagement webinars and workbooks!

<https://www.instituteforbetterhealth.com/portfolio-items/patient-caregiver-and-community-engagement-learning-series/>



# Connecting People & Community for Living Well

Transforming local care and supports to build and sustain wellbeing



Our team works provincially with rural multi-sector community teams to build and sustain the wellbeing of local underserved populations such as seniors impacted by dementia, and others who may benefit from enhanced support within their community.

[At-a-Glance](#)

[Model & Resource Bundle](#)

[Our Team](#)

[Progress to Date](#)

## Featured

CPCLW [final evaluation report and summary](#) now available

Highlighting outcomes for five Alberta communities, factors influencing wellbeing, implementation processes, impacts and lessons learned

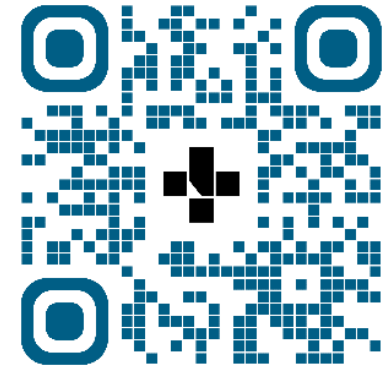
## Local Stories & Case Studies

Examples of community partnerships, action and successes across Alberta.

[More >](#)

## Evidence of Impact

- [Activities & impact infographic \(2020-2022\)](#)
- [Applied Research Summary, Health Canada Grant \(2023\)](#)
- [CPCLW final evaluation report & Summary \(2023\)](#)

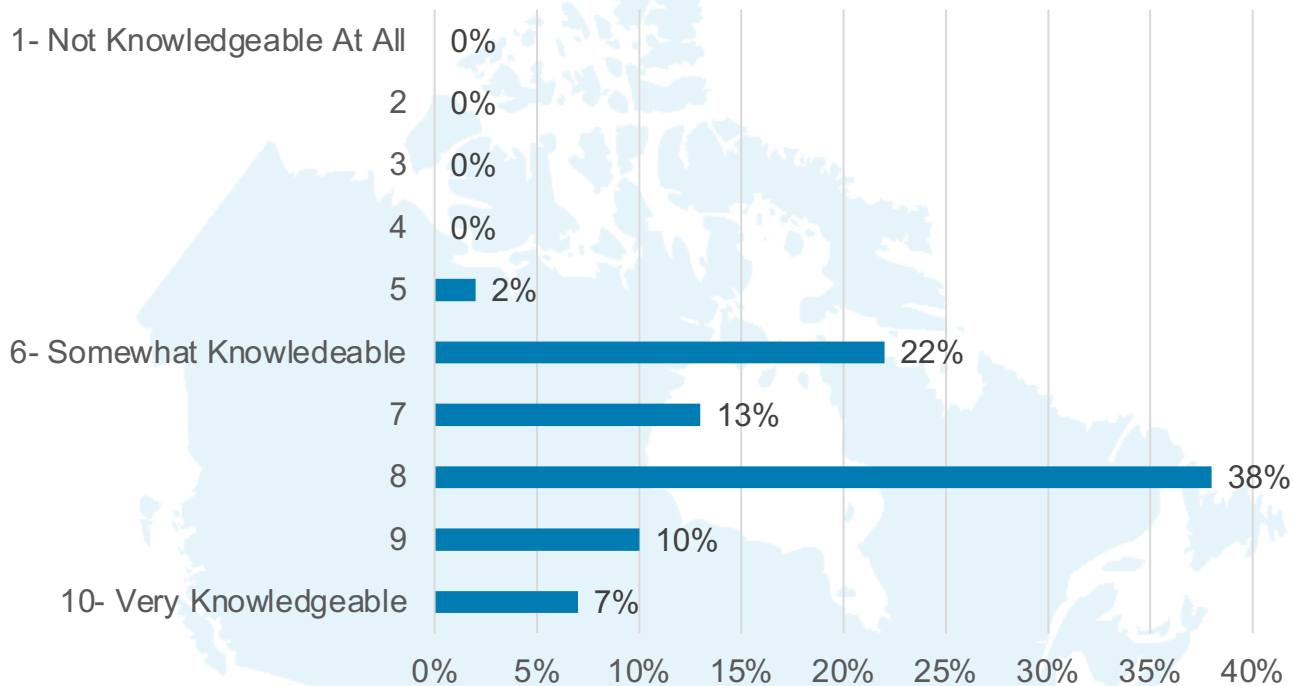


- Email us at: [cpclw@ahs.ca](mailto:cpclw@ahs.ca)
- Visit our website at: [www.ahs.ca/cpclw](http://www.ahs.ca/cpclw)
- View our playlist on [Healthy Aging Alberta - YouTube](#)

# Poll Results: Your Knowledge About Today's Topic

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As a result of today's session, how knowledgeable are you about patient and caregiver engagement within integrated care?





# Snowball

In one word, describe your experience being part of the virtual community today.

*Let us know via the chat box*



# Word Cloud- One word to describe being part of the virtual community today

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# References

Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*. 2013;32(2):223-231.

Contandriopoulos AP, Denis JL, Touati N, C. R. *The integration of health care: dimensions and implementation*. Montréal: Université de Montréal;2003.

Goodwin N. Understanding Integrated Care. *International Journal of Integrated Care*. 2016;16(4).

Lewis R, Rosen R, Goodwin N, Dixon J. *Where next for integrated care organisations in the English NHS*. London, The Nuffield Trust. 2010.