

Patient Engagement in Cancer Research Community of Practice



**COMMUNITY
OF PRACTICE**
patient engagement
in cancer research

Judy Needham
on behalf of the
Canadian PE CoP Members

May 15, 2024

Gramma



Volunteer



Patient / Cancer Survivor

Mom

Wife


**Retired, Director
Corporate Marketing**



Affiliations / Disclosures



* Canadian Cancer Trials Group  Groupe canadien des essais sur le cancer

*  **COMMUNITY OF PRACTICE**
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 Canadian
Cancer Clinical
Trials Network

**BC
CAN
CER** RESEARCH
Provincial Health Services Authority

NCI National Clinical
Trials Network
a National Cancer Institute program

 **BIG** against
breast cancer

* programs
sponsored by
the  **Canadian
Cancer
Society**

Pfizer grant recipient
3CTN Patient Engagement Training Pathway



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Conception/Background



Objectives



Membership



Topics



Feedback Gathered



Future Direction

Today's Agenda

Conception/Background



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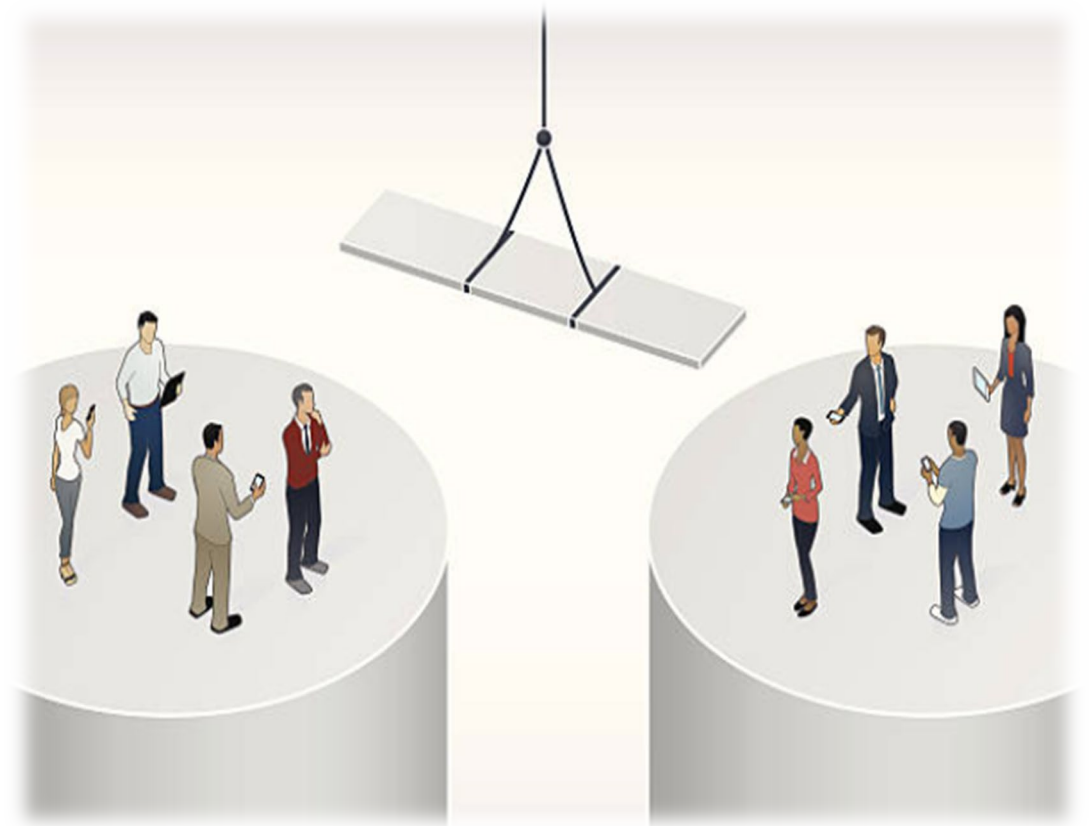
The Canadian Landscape

- Several widely recognized examples of patient engagement in research initiatives,
- Less well-known, but great work happening quietly within many organizations.
- Several organizations seeking out best practices.
- Are there opportunities for
 - collaboration, resource sharing, minimizing duplication of effort,
 - gaining perspective and awareness of ongoing initiatives, lessons learned, and best practices?



Objectives

- Create a virtual space to **bridge siloed efforts**
- Build relationships and connections among those involved in PE in cancer research (**Connection**)
- Facilitate partnerships to address common PE goals and initiatives (**Collaboration**)



“In the longer run and for wide-reaching issues, more creative solutions tend to come from imaginative interdisciplinary collaboration.” — Robert Shiller

Method

Initiated in 2022

- Executive Sponsor and Secretariate support
- Establishment of an initial Steering Committee
- CoP Framework development:
 - Strategic Plan
 - Terms of Reference
 - Call for membership
 - Communications/Meeting plan
- Feedback mechanism (annual survey)
- Growth and Sustainability



Canadian Cancer Society
Société canadienne du cancer



Method



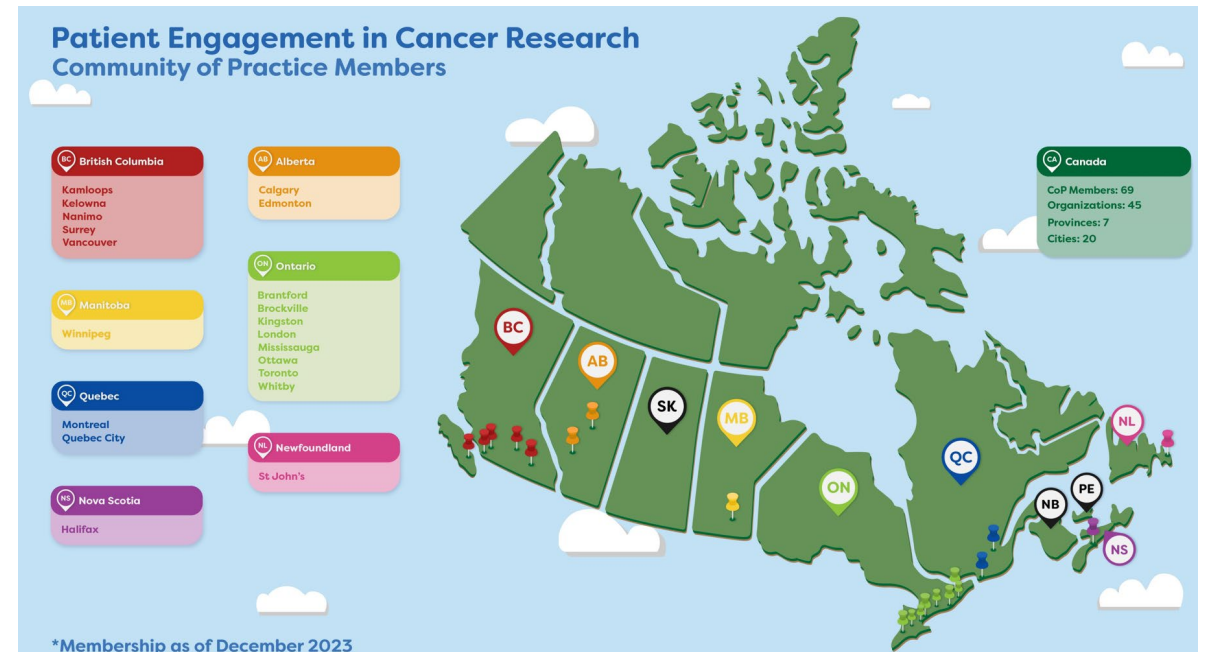
Inaugural Steering Committee

Member	Organization	Category
Jennifer Wilson (Initiator)	Canadian Cancer Society	Charitable Organization, Funder
Judy Needham (Initiator)	Canadian Cancer Trials Group	Research Sponsor - Academic
Antonia Palmer	Ontario Institute for Cancer Research	Academic Research Institute
Stephanie Michaud	BioCanRx	Research Network and Funder
Stephen Sundquist	3CTN	Research Network
Patrick Sullivan	Childhood Cancer Canada Board	Charitable Organization, Funder
Kim Badovinac	Canadian Cancer Research Alliance	Research Network
Robin Urquhart	Dalhousie University	Academic Research Institute
Judit Takacs (Secretariat)	Canadian Cancer Society	

Results - Membership

By December 2023, the CoP included 69 members from 45 organizations and 7 provinces representing:

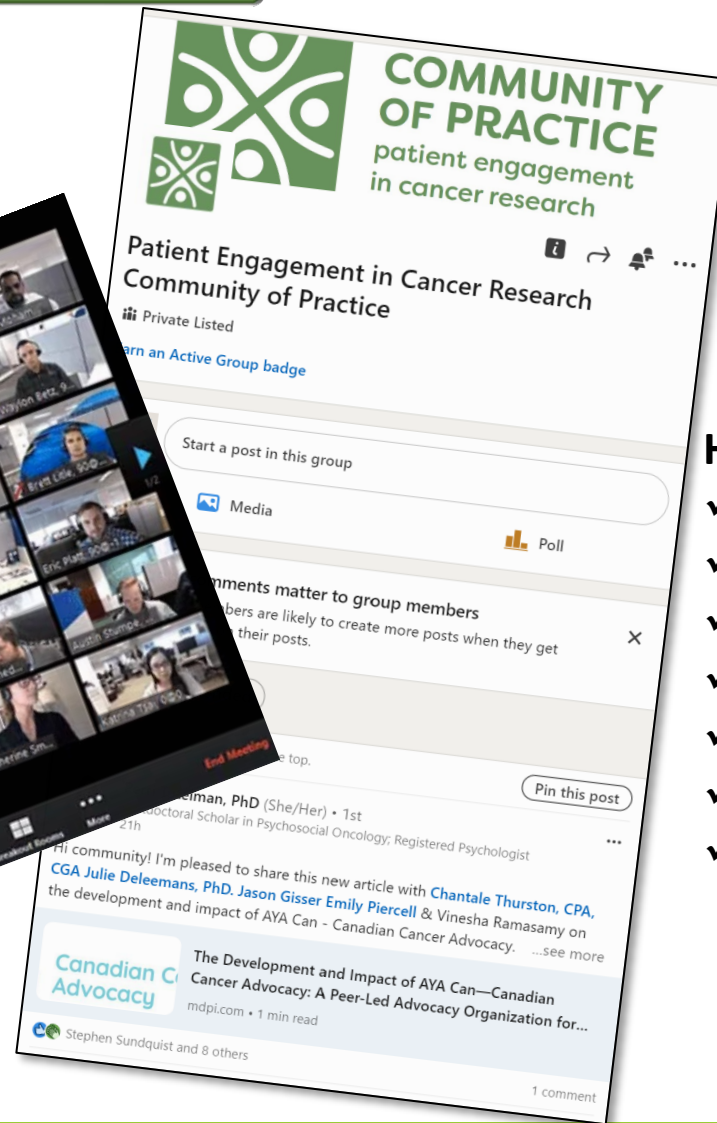
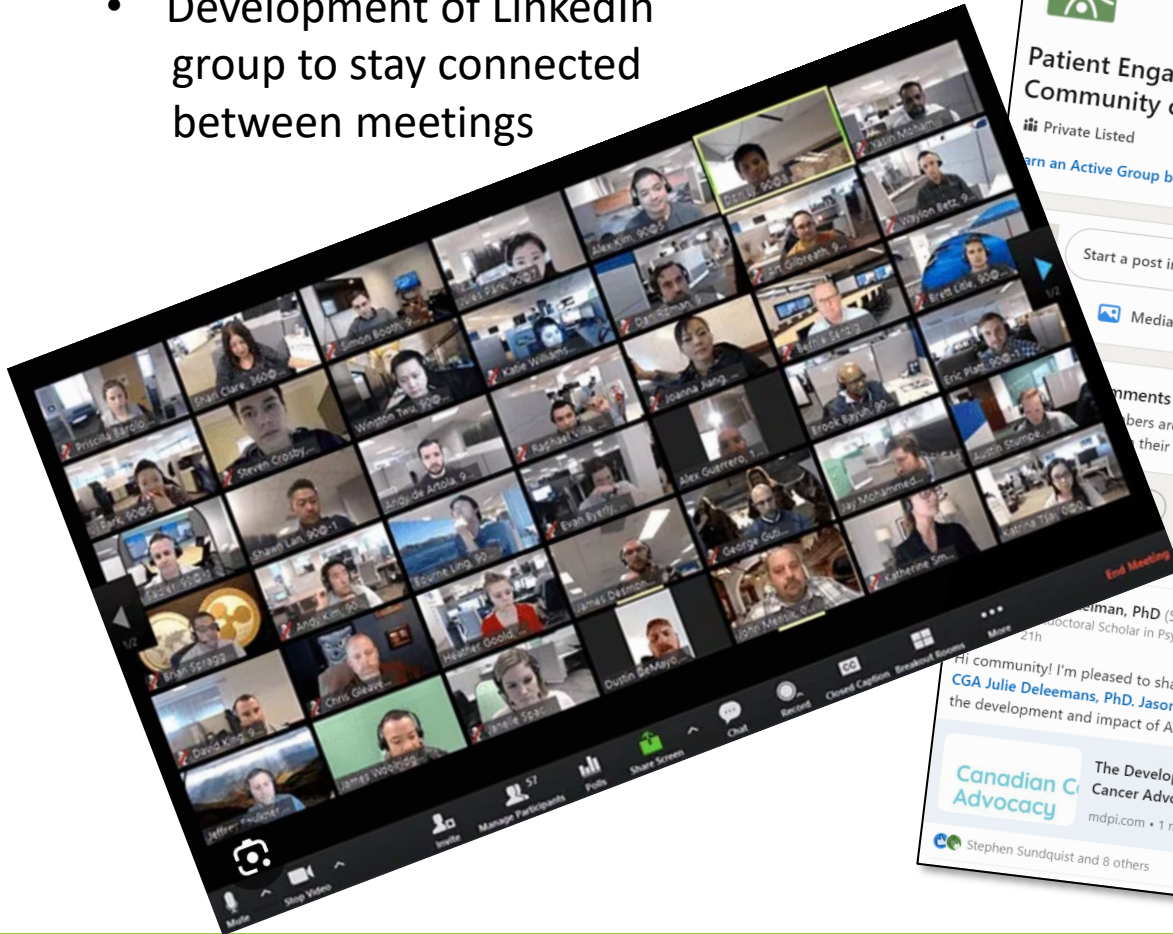
- Research Institutions
- Universities
- Trial Sponsors
- Cancer Centres/Organizations
- Health Care Professional Associations
- Patient Advocacy Groups
- Provincial Agencies
- Government
- Industry



Results - Communications

To Date

- 11 virtual meetings
- Development of LinkedIn group to stay connected between meetings



Has Resulted In

- ✓ Assistance in finding Patient Partners
- ✓ Finding/Sharing Best Practices
- ✓ Finding/sharing tools of engagement
- ✓ Some elimination of duplication of effort
- ✓ EDI discussions and learnings
- ✓ Valuable connections/relationships
- ✓ A broader understanding of the multiple number of initiatives in Canada

Call Topics



Topic	Speaker	Meeting date
CoP Launch – Getting to know who’s participating	CoP Steering, All, J Needham	April 2022
Community prioritization – keynote topics, staying connected, sharing	Cop Steering, All, S. Sundquist	June 2022
Engaging patients in a specific clinical trial	Ottawa Hospital Research Institute M. Foster	September 2022
Online learning modules for patient engagement	CIHR – IMHA D. Richards/L. Hunter	November 2022
Future directions for patient-oriented research	CIHR – SPOR – Amy Lang	January 2023
EDI - Equity, diversity and inclusion in patient engagement	CPAC – C. Louzado	March 2023
Patient-centered approach to clinical trials	Colorectal Cancer Canada – B. Stein	May 2023
Patient Engagement in Academic Cancer Clinical Trials	Canadian Cancer Trials Group – Y. Murray	October 2023
Patient engagement in research – The Learning Institute	BioCanRx – L. Lindo, S. Patacairk	January 2024
Patient research prioritization	AYA Can, Myeloma Canada, NL Public Interest Group – S.Savas, C.Thurston, M.Elias	March 2024
Indigenous patient engagement	London Health Sciences Center – L. Jackson	May 2024

Results - Evaluation



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2023 Survey

Community of Practice evaluation includes an annual member survey. The 2023 survey indicated positive experiences and tangible value in:

New relationships or connections	43%
New patient engagement resource or strategy development	33%
New cross-organizational collaborations	19%
Other outcomes or successes	5%
Total	100%

Results - Operation



CoP operation currently includes:

- 4 annual, 90-minute virtual meetings (January, March, May, October)
- 2-3 annual Steering planning meetings
- Smaller subgroups ('work groups') who meet separately to collaborate on a tangible project
- LinkedIn group for networking and resource/event sharing between meetings
- Annual evaluation (survey deployed every May meeting)
- Facilitation, group management, technology support from our sponsor (CCS)

Future Direction

1. Survey – What would you most like to learn from the Community of Practice?

Mentoring and training of Patient Advocates	29%
Planning and reviewing of engagement	23%
Innovations in patient engagement	18%
Patient Engagement in Clinical Trials	18%

- Requested Upcoming Topics
 - Evaluating data, and creating metrics/key performance indicators, demonstrating value
 - Patient partners informing best practices - what do they want out of their experience, how do they want to work?
- Consideration of international membership requests
- 2024 Survey of members underway

Patient Engagement in Cancer Research Community of Practice Members

BC British Columbia
Kamloops
Kelowna
Nanimo
Surrey
Vancouver

AB Alberta
Calgary
Edmonton

ON Ontario
Brantford
Brockville
Kingston
London
Mississauga
Ottawa
Toronto
Whitby

MB Manitoba
Winnipeg

QC Quebec
Montreal
Quebec City

NL Newfoundland
St John's

NS Nova Scotia
Halifax

CA Canada
CoP Members: 69
Organizations: 45
Provinces: 7
Cities: 20



*Membership as of December 2023

Acknowledgements



Current Steering Committee

- Jennifer Wilson, CCS
- **Stephanie Michaud, BioCanRx**
- Judy Needham, CCTG
- **Stephen Sundquist, 3CTN**
- Don Wood, 3CTN
- Meera Rayar, UBC
- Sevtap Savas, Memorial University
- Justin Noble, OICR

Founders

- Judy Needham, CCTG
- Jennifer Wilson, CCS
- Stephen Sundquist, 3CTN
- Kim Badovinac, CCRA
- Robin Urquhart, Dalhousie University
- Stephanie Michaud, BioCanRx
- Antonia Palmer, Kindred Foundation
- Patrick Sullivan

Canadian Cancer Society
(Executive Sponsor)



Canadian Cancer Society **Société canadienne du cancer**



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Thank You

Conclusions



The CoP welcomes anyone with interest to join!

Email the Secretariat (judit.takacs@cancer.ca) or visit our [LinkedIn page](#) to join.

The screenshot shows a LinkedIn group page for the 'Community of Practice: Patient Engagement in Cancer Research'. The group is private and listed, with 65 members. The page features a header with the group's logo and name, a 'Start a post in this group' button, and navigation options for 'Media' and 'Poll'. Below the header, there are tabs for 'All' and 'Recommended'. A post by Rebecca Mercer, Program Manager at Applied Research | Operations Management | Research, is visible, dated 4 days ago. The post content includes 'Hi Everyone!' and 'I wanted to make sure the 2024 ARCC Conference was on your radar'. To the right of the group page, an 'Analytics' section shows activity over the last 15 days: 31 active members (up 24%), 2 new members, 2 posts (up 100%), and 134 post views (up 79%).