Canadian Cancer Research Alliance

Alliance canadienne pour la recherche sur le cancer

Patient Involvement in Cancer Research Program

Programme de Participation des Patients à la recherche sur le cancer

Evaluation of the Second PIP held in Ottawa from November 1-5, 2019 and Recommendations for Future Programs

Contents

ACKNOWLEDGEMENTS

The PIP was made possible by the financial support of the CIHR Institute of Cancer Research (ICR) and the following organizations: Alberta Cancer Foundation and Canadian Partnership Against Cancer, who each supported three patient partners; Canadian Cancer Society, Fonds de recherche du Québec - Santé, and The Terry Fox Research Institute, who each supported two patient partners; and BioCanRx, C^{17}, Cancer Research Society, Ovarian Cancer Canada, Prostate Cancer Canada, and Saskatchewan Cancer Agency, who each supported one patient partner.

We would also like to acknowledge the members of the working group who helped shape the 2019 program: Ms. Ruth Ackerman, Dr. Cindy Bell, Dr. Stephanie Michaud, Ms. Theresa Radwell, Dr. Stephen Robbins, Mr. Barry Stein, and Mr. Patrick Sullivan.

A very special thank you to Ms. Alyssa Vito, a PhD candidate from Dr. Karen Mossman's laboratory at McMaster University, who in addition to being a science partner developed and provided two webinars for participants, addressed and supported via email participant questions, and presented a poster as part of the "Scientific Posters 101", a session within the PIP curriculum. Other presenters for the tailored PIP curriculum included: Dr. Louisa Salemi, Ms. Nancy Mason MacLellan, Mr. Patrick Sullivan, Mr. Barry Stein, Ms. Madison Foster, Ms. Nathalie Baudais, and Mr. Nader El-Sayes. Participants benefitted greatly from the information and expertise these individuals shared.

Eight science partners were recruited from the CIHR ICR Early Career Investigator Meeting: Drs. Julia Burnier, Jacqueline Galica, Janel Kopp, Sampath Loganathan, Marco Magalhaes, Samantha Mayo, Alyson Mahar, and Karla Williams. They, along with Ms. Alyssa Vito, were invaluable contributors to the program by helping to interpret the science for patient partners.

The most vital component of PIP is the active participation of its participants. The original PIP cohort of 14 individuals and the 2019 cohort of 20 individuals all diligently attended an action-packed program, interacted with researchers, and generously provided their ideas on how the program could be improved going forward. The long hours spent at the program and the preparation they did before attending the program is a testament to their dedication to enhancing the voice and role of patients in the cancer research enterprise.

And finally, the success of PIP is largely due to the perseverance of Mr. Patrick Sullivan who not only provided the impetus for the program but continues to inspire other patient advocates with his passion and commitment.

This report was completed by Kim Badovinac, who coordinates PIP.

SUMMARY

The second **P**atient **I**nvolvement in Cancer Research **P**rogram (PIP) was held from November 1 to 5, 2019 in Ottawa. The program was attended by 20 patients/caregivers and supported by 12 Canadian Cancer Research Alliance (CCRA) member organizations.

Participants rated the program as worthwhile. At five to six weeks post-program, all were able to identify specific learnings and insights useful to their ongoing advocacy work and/or were able to clarify how they would go-forward in their research advocacy efforts. In addition, positive change from 2017 to 2019 was found among delegates of the Canadian Cancer Research Conference (CCRC) in terms of their familiarity and interest in involving patients in cancer research.

Patient connections/networking was identified as a vital component of the program and, as PIP grows in terms of the number of participants involved, adequate time needs to be provided to ensure this happens. Patient resources and a forum for continued dialogue were again identified as important.

In terms of program improvements, many suggestions were articulated by participants and science partners. Improved/streamlined communication coming from PIP, CCRC and the CIHR Institute of Cancer Research Early Career Investigator meeting was identified as needed. In addition, better preparation of co-chairs – both patient and science co-chairs – would enhance this experience for patients as well as the delegates attending the CCRC. Poster sessions continue to need enhancement in order to be valuable to PIP participants and the ideas generated by participants and science partners will be very helpful in informing how this is done.

This report will be used to inform CCRA members and the 2021 CCRC Executive Planning Committee on their decision-making regarding continued patient involvement. A working group for PIP will be struck in fall 2020 and this group will look at how to re-tool the program. PIP operates within an environment where there are a growing number of learning opportunities for patient research advocates. How best to integrate PIP within this larger context is another vital consideration for the working group. In this vein, CCRA members may also want to consider whether to support patient advocates to attend educational opportunities beyond PIP.

BACKGROUND

The impetus for the Patient Involvement in Cancer Research Program (PIP) was provided by Mr. Patrick Sullivan, one of the patient/family representatives on the Board of the Canadian Cancer Research Alliance (CCRA) back in 2016. Since Patrick's son Finn succumbed to Rhabdomyosarcoma, Patrick has become a passionate childhood cancer advocate as well as President and a founder of the Team Finn Foundation and a founding member of Ac2orn (Advocacy for Canadian Oncology Research Network). Patrick had attended patient advocacy programs in the U.S. and felt strongly that a program was needed as part of the biennial Canadian Cancer Research Conference (CCRC).

Although we use the word "patient" in the title of this program, we mean all people affected by cancer. This includes patients, caregivers, and family members who want to learn more about cancer research and ensure that cancer research is informed by the patient voice and lived experience.

The CCRA Board and the 2017 CCRC Executive Planning Committee (EPC) for the CCRC unanimously endorsed Patrick's proposal, although there were several months of indecision on the part of the CCRA Executive Office on how best to carve out a program when the budget had already been determined for the CCRC and no provisions existed to support it. CCRA member organizations, however, rallied to the cause and agreed to both identify and support patients to attend, with additional expenses being offset by the CIHR Institute of Cancer Research. The EPC formalized its commitment by adding a conference objective related to patient involvement in research – "Enhance patient involvement in cancer research in Canada."

CCRA	Canadian Cancer Research Alliance
CCRC	Canadian Cancer Research Conference
CIHR	Canadian Institutes of Health Research
ECI	Early Career Investigator
EPC	Executive Planning Committee
LOC	Local Organizing Committee
SPC	Scientific Program Committee

Other elements introduced during the 2017 inaugural year were: inclusion of two patient advocates on the Scientific Planning Committee (SPC); involvement of patient advocates as session co-chairs (5/25 sessions); incorporation of a patient presentation in the public lecture; and addition of a new award category to recognize exceptional leadership in patient involvement in cancer research. In addition, patient/family representatives for the CCRA Board would be recruited from among the PIP participants through a self-nomination process.

The experience and feedback received from patients and sponsors of the 2017 program helped shape the 2019 program. This report details the 2019 program and the subsequent feedback that will be used to guide proposed program changes to PIP going forward.

PROGRAM DESCRIPTION

PARTICIPANTS

The original target for the 2019 program was 16 participants. However, there was a great deal of demand for the program and, with the approval of CIHR ICR, the program's main sponsor, the ceiling was raised to 20.[1]

Participants consisted of those supported through the CCRC because of their involvement on the EPC/SPC (n=2), those put forward by supporters (n=11), and those who self-identified to the Executive Office and for whom supporters elected to support (n=7). Four of the 20 participants had also attended the inaugural program. Participant characteristics are provided in Figure 1 below.

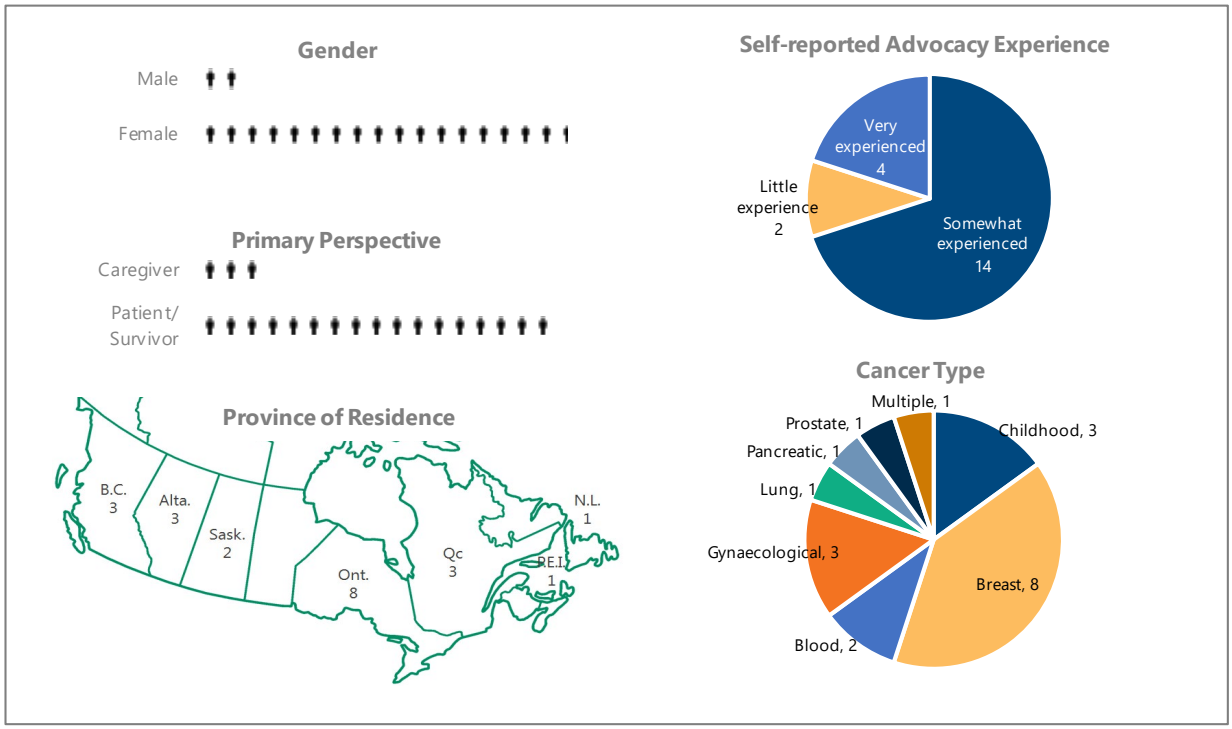


Figure 1. PIP 2019 participant characteristics

The 2019 participants had greater geographic diversity, more self-reported advocacy experience, and more diversity in terms of their cancer experience than the 2017 group. Figure 2 shows participants along with their science partners.

[1]Of note, Alberta Cancer Foundation had additional candidates for participation, so demand was around the 25-person mark. Note that PIP is only made available to CCRA member organizations so it is expected that interest in the program would likely be greater if it was promoted to other organizations.

Figure 2. 2019 PIP participants and science partners

PROGRAM

Feedback gathered from the 2017 program focused on three major areas for improvement:

1. Enhance profile/improve visibility of PIP participants
2. Provide more interactions with science partners and other researchers
3. Improve the poster experience

Efforts were made to construct the 2019 program to address these specific areas as follows.

1. Enhance profile/improve visibility of PIP participants
   - Three of the participants from the 2017 PIP participated on the 2019 CCRC committees.
   - Language changes were made - patients referred to as "patient partners" and "patient advocates"; mentors to "science partners."
   - PIP participants had identifiable name tags/lanyards.

- All PIP patients participated as session co-chairs and/or session panelists (also related to the second area of improvement). On page 8, all 19 CCRC sessions where patients were involved are identified.[2]
- One-page of printed scientific handbook provide a brief description of the program and listed PIP participants, science partners and supporters. All three groups were also recognized in the conference opening and closing.
- PIP participant pictures and brief bios were featured on the conference app.

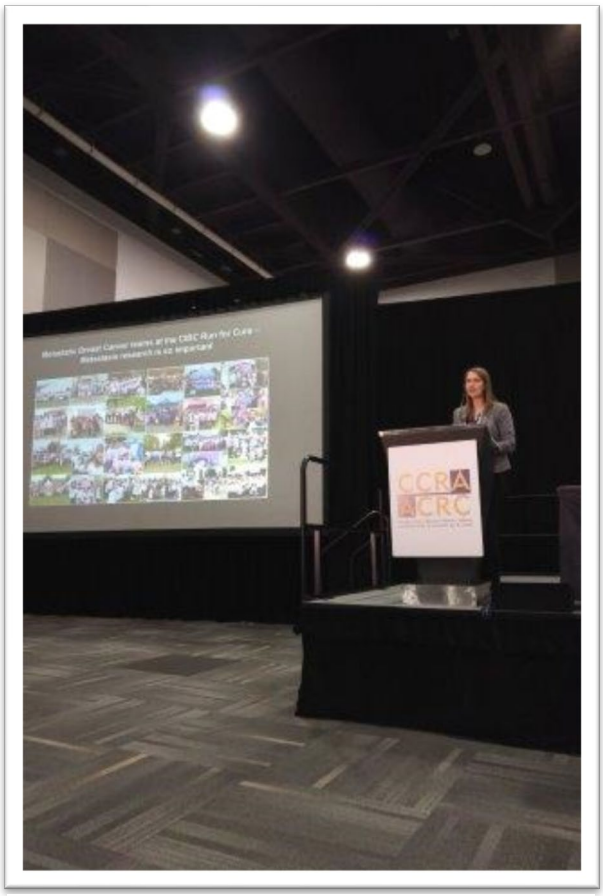


Figure 3. Ms. Nathalie Baudais, Patient Partner, introducing the Metastasis concurrent on behalf of Ms. Heather Douglas.

2. More interactions with science partners and other researchers
   - PIP was formally integrated with the CIHR ICR ECI – PIP participants attended the ECI Friday night networking event and 8/9 science partners who supported this program were ECIs.[3]
   - PIP participants, science partners and sponsors attended a joint breakfast on the first day of the CCRC.
   - Patient partners and science partners were together for most breakfast and lunch breaks and science partners in many cases sat with their patient partners during the plenary sessions and some of the concurrent sessions.
   - The ratio of science partners to patients was boosted (we aimed for two patient partners to one science partner). One science partner was bilingual and paired with two PIP participants from Quebec.

[2]Mr. Denis Raymond, although not a part of 2019 PIP due to scheduling differences, participated in 2017 PIP and was a member of 2019 LOC. Mr. Raymond co-chaired two concurrent sessions and these are included in the 19 identified.

[3]Of note, at the time of abstract submission, participants were asked about their interest in participating in the patient program. Of the 590 people who submitted abstracts, 148 (25%) expressed an interest in being a science partner. There were no differences in terms of a gender, area of science, or registration category among those who indicated an interest in being a science partner and those who did not. There was, however, a slight difference by geography – proportionately more abstract submitters from BC and fewer from QC indicated an interest in PIP. This list was cross-referenced with the list of ECIs (17 ECIs were among the abstract submitters indicating an interest in PIP). From there, 8 ECIs agreed to participate in the program.

PIP Participant as co-chairs/panelists

CONFERENCE OVERVIEW

Saturday, November 2, 2019						
12:20 pm	Community Event – *Rideau Canal Atrium*					
Sunday, November 3, 2019						
7:30 am	Breakfast – *Canada Hall 2 and 3*					
8:30 am	Welcome Remarks – *Canada Hall 1*					
9:20 am	**Plenary Session: Novel Cancer Immunotherapies** – *Canada Hall 1*					
11:00 am	Break – *Canada Hall 2 and 3*					
11:30 am	**A1** – Innovations in Cancer Proteomics – *Room 214*	**A2** – The Impact of Primary and Metastatic Tumour Microenvironments on Cancer Growth and Response to Therapy – *Room 215*	**A3** – Pediatric Oncology: A new frontier - navigating the opportunities and ethical challenges of precision medicine – *Room 202*	**A4** – Prevention: Enriching Knowledge by Addressing Time – *Room 212*	**A5** – Indigenous Populations and Cancer – *Room 203*	
1:00 pm	Lunch– *Canada Hall 2 and 3*					
2:00 pm	**B1** – Imaging and Metabolic Profiling of Cancer – *Room 214*	**B2** – Innovations in Cancer Care – *Room 215*	**B3** – Integrating Elements of a Palliative Care Approach – *Room 202*	**B4** – Stakeholder and Patient Engagement in Clinical Trials and Patient-Oriented Research – *Room 212*	**B5** – Hot Topics in Occupational Cancer Prevention in Canada – *Room 203*	**B6** – Metastasis – *Canada Hall 1*
3:30 pm	Poster Session and Exhibits – *Canada Hall 2 and 3*					
5:00 pm	Welcome Reception – *Canada Hall 2 and 3*					
Monday, November 4, 2019						
7:20 am	Breakfast – *Canada Hall 2 and 3*					
8:30 am	**Plenary Session: Cancer Genetics and Precision Oncology** – *Canada Hall 1*					
10:00 am	Rapid Fire Presentations – *Canada Hall 1*					
10:30 am	Break – *Canada Hall 2 and 3*					
11:00 am	**C1** – Model Systems in Cancer Research – *Room 214*	**C2** – Cancer Stem Cells and Cellular Plasticity – *Room 215*	**C3** – Understanding the Fundamental Basis of Cancer Through the Study of Rare Tumours – *Room 202*	**C4** – Getting Real: The Expanding Role of Real-World Evidence (RWE) in Oncology – *Room 212*	**C5** – Cancer Prevention and Screening: Selected Updates – *Room 203*	
12:30 pm	Lunch – *Canada Hall 2 and 3*					
1:30 pm	**Plenary Session: CCRA Awards Presentation** – *Canada Hall 1*					
3:00 pm	Poster Session and Exhibits – *Canada Hall 2 and 3*					
4:00 pm	**D1** – Microbiome – *Room 214*	**D2** – Lessons from Aging – *Room 215*	**D3** – Poor Survival Cancers – *Room 202*	**D4** – Tackling Inequity in Cancer Care – *Room 212*	**D5** – Cannabis, Vaping and E-cigarettes: Canada's Evolving Drug Market and Implications for Cancer Control – *Room 203*	
Tuesday, November 5, 2019						
7:30am	Breakfast – *Canada Hall 2 and 3*					
8:30 am	**E1** – Mechanisms of Cancer Resistance – *Room 214*	**E2** – Cancer Immunotherapy – *Room 215*	**E3** – Meeting Healthcare Needs in the 'Era of Cancer Survivorship' – *Room 202*	**E4** – Accelerating Clinical Trials in a Genomic-driven Era – *Room 212*	**E5** – Consortium Based Research – *Room 203*	
10:00 am	Break – *Canada Hall 2 and 3*					
10:30 am	**Plenary Session: The Future of Cancer Research** – *Canada Hall 1*					
12:00 pm	Closing Remarks – *Canada Hall 1*					

Patient and science partners were paired as follows:

PATIENT PARTNERS	SCIENCE PARTNERS	SCIENCE PARTNERS' AREAS OF SCIENCE
Mme Sylvie Halde Mme Lucie Piché	Dr. Julia Burnier, McGill University	Uveal melanoma; genomics; liquid biopsies; proteomics
Ms. Adrienne Co-Dyre Ms. Debi Lascelle Ms. Debra Walker	Dr. Jacqueline Galica, Queen's University	Psychosocial needs of post-treatment cancer survivors
Dr. Vera Samarkina Ms. Danielle Smith	Dr. Janel Kopp, The University of British Columbia	Cellular and molecular mechanisms underlying the development of pancreatic diseases
Ms. Nathalie Baudais Ms. Antonia Palmer	Dr. Sampath Loganathan, Lunenfeld-Tanenbaum Research Institute	Identifying tumor suppressors; driver genes
Ms. Ruth Ackerman Dr. Don Desserud	Dr. Marco Magalhaes, University of Toronto	Oral pathology and cancer; cell invasion and metastasis
Ms. Melissa Coombs Ms. Cathy McCallum	Dr. Samanatha Mayo, University of Toronto	Improving the long-term health outcomes of cancer survivors
Ms. Doreen Edward Ms. Inge van Galen-Bouman	Dr. Alyson Mahar, University of Manitoba	Gaps in the understanding of outcomes and issues for underfunded and high mortality cancers, studying the cancer journey for individuals with severe psychiatric illness
Ms. Louise Bird Ms. Marilyn Sapsford Mr. Bill Sutherland	Ms. Alyssa Vito, McMaster University	Immunotherapy treatments for triple-negative breast cancer
Ms. Heather Douglas Ms. Catherine Hays	Dr. Karla Williams, The University of British Colubia	Key mechanisms that regulate cancer cell metastasis and developing cancer diagnostics though small-particle analysis

Figure 4. Ms. Alyssa Vito, Science Partner, presenting her research during the Cancer Immunotherapy concurrent.

3. Improve Poster Experience
    - Two pre-program webinars were developed and provided by Ms. Alyssa Vito. The first, "Cancer Biology 101" was held in mid-September; the second, "Emerging Therapeutics" was held in mid-October. Both were recorded and posted to YouTube for ongoing reference by PIP participants.
    - A glossary of terms and a list of abbreviations/acronyms were shared with participants prior to the program.
    - Pre-conference calls were conducted with each of the PIP participants to document their research interests. A personalized list of 10 posters was created for each PIP participant.
    - The PIP curriculum included a "science poster 101" session to help orient participants to scientific posters.
    - Abstracts were included in the conference in app, with a searchable interface.[4]
    - A lunchtime lecture by Dr. Robin Urquhart was organized to provide specific content related to survivorship and patient-health provider communication, areas identified as important to many PIP participants.

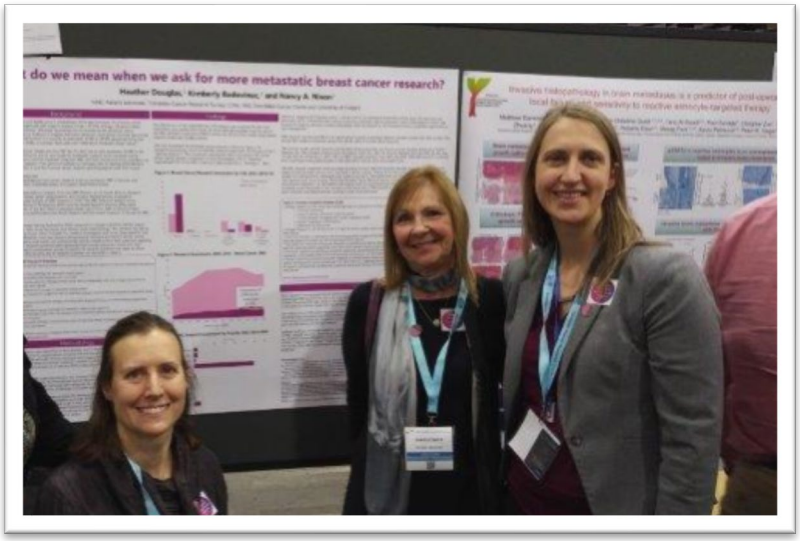


Figure 5. From left to right: Ms. Heather Douglas, Ms. Danielle Smith and Ms. Nathalie Baudais during the poster session.

[4]There were problems with the conference app that precluded meaningful use for poster identification.

PIP 2019 AGENDA

The PIP agenda was as follows:

DAY 1 **FRIDAY NOV. 1**	DAY 2 **SATURDAY NOV. 2**	DAY 3 **SUNDAY NOV. 3**	DAY 4 **MONDAY NOV. 4**	DAY 5 **TUESDAY NOV. 5**
PIP Huddle CIHR ICR Early Career Investigator Meeting - Networking Event	PIP Curriculum Community Event	CCRC **Supporter breakfast, with CCRC/PIP Supporters, PIP Participants, and Science Partners*	CCRC **Lunchtime presentation by Dr. Robin Urquhart*	CCRC PIP Wrap-up & Debrief

"Opportunity to meet with PIP attendees was the best supporter recognition."

Figure 6. Mr. Patrick Sullivan (standing), Mr. Barry Stein and Ms. Madison Foster, presenters at the Research Advocacy Panel as part of the PIP Curriculum.

Details of the PIP Curriculum were as follows:

TIME	TOPIC	PRESENTER(S)
8:30-9:00 am	BREAKFAST **Welcome & Program Overview**	Ms. Kim Badovinac, PIP Coordinator
9:00-9:30 am	**CCRC Overview**	Dr. Louisa Salemi, Conference Lead
9:30-9:45 am	**Conference App Orientation**	Dr. Louisa Salemi, Conference Lead
9:45-10:00 am	**CIHR Strategy for Patient-Oriented Research (SPOR): Update**	Ms. Nancy Mason MacLellan, Manager, CIHR Major Initiatives
10:00-11:00 am	**Research Advocacy Panel**	• Mr. Patrick Sullivan, President/founder, Team Finn Foundation; founding member of Ac2orn (Advocacy for Canadian Oncology Research Network) • Mr. Barry Stein, President & CEO, Colorectal Cancer Canada • Ms. Madison Foster, Research Assistant, Blueprint Translational Research Group, Ottawa Hospital Research Institute
11:00-11:10 am	**Preparing a "Patient Advocate" Resume**	Ms. Nathalie Baudais, Patient Advocate
11:10 am-11:15 am	**Scientific Posters "101": Overview**	Ms. Kim Badovinac, PIP Coordinator
11:15 am-Noon	**Poster Presentations**	• Ms. Alyssa Vito • Mr. Nader El-Sayes • Mr. Barry Stein
Noon-12:45 pm	LUNCH	

OBSERVATIONS & FEEDBACK

DATA SOURCES

The program was evaluated in the following ways:

- A brief paper-based questionnaire on the relevancy and applicability of the information presented (N=18) was completed at the end of the program.
- A dotmocracy exercise to rate the top sessions of the CCRC from the patient perspective (N=18) was also completed at the end of the program. This was designed to assess the meaningfulness of the scientific sessions to the patients and help in future planning.
- A group debrief with participants (N=19), two mentors, CCRA Board patient/family representatives, Mr. Barry Stein, and Dr. Stephen Robbins, was held at the conclusion of the program to gather immediate impressions and insights on the program as well as suggestions for improvements.
- Post-program contacts were made with all participants (by phone) as well as scientific partners (by phone or email) five to six weeks after the program to gather lasting insights. Four structured questions were used to guide the discussion with the participants: What was your most significant learning? What do you hope to do with the information you learned as a result of attending the program? How could the program improve the interaction between patients and scientists? What other suggestions do you have for improving the program for the next go-round?
- The online conference evaluation questionnaire, which was sent to all delegates to complete, included specific items related to patient involvement in cancer research. Responses collected in 2017 were compared with those collected in 2019.

Figure 7. From left to right: Dr. Julia Burnier (Science Partner), M^me^ Sylvia Halde (Patient Partner), Dr. Anne-Marie Mes-Masson (PIP Supporter), and M^me^ Lucie Piché (Patient Partner).

In addition to the data above, many participants shared their experience online or with their sponsoring organization. Some of these are provided in Appendix A.

PAPER-BASED QUESTIONNAIRE

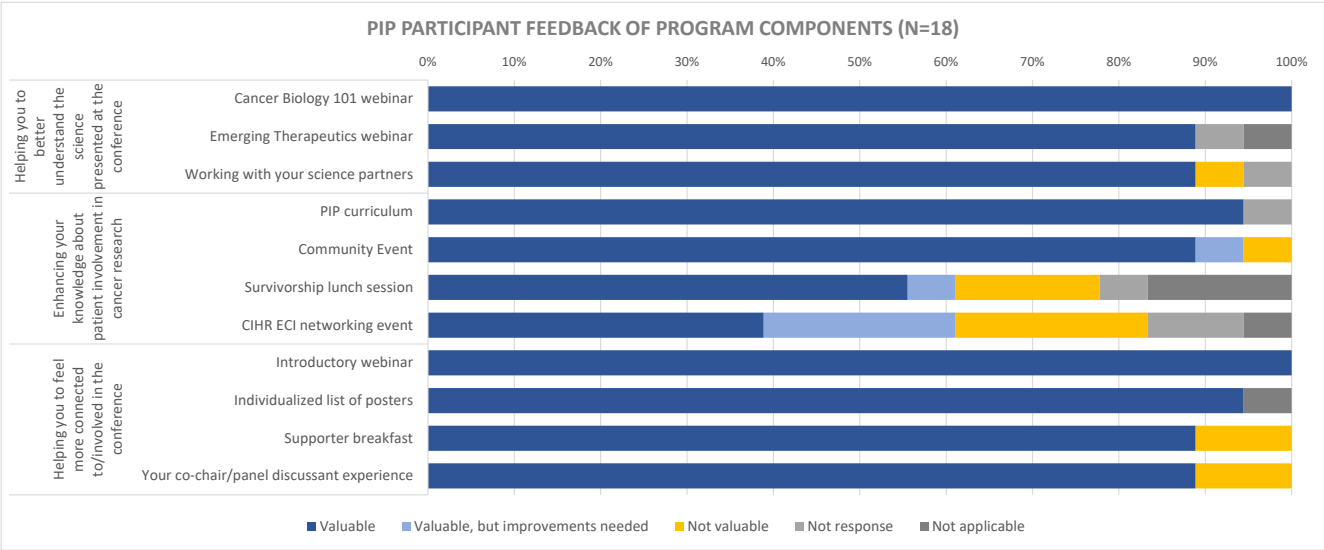
Eighteen participants completed the post-program paper-based questionnaire. One participant was too ill to participate in the program and another did not submit a completed questionnaire. A denominator of 18 was used in calculating the results.

All 18 participants felt that participation in PIP was worthwhile. Almost all (17/18) indicated that they would use the information that they learned to advocate or influence change.

Figure 8. From left to right: Mr. Bill Sutherland (Patient Partner), Ms. Debi Lascelle (Patient Partner), and Dr. Jennifer Jones (Concurrent Session Presenter).

Feedback on specific program components is provided in the graph on page 16. Areas for improvement included the venue for the ECI networking event, which was not suitable for all participants due to the venue size, lack of seating, and noise level. The survivorship lecture session was perceived to be ill-placed as participants felt that preserving some downtime during their meal breaks was important.

It is noteworthy that while most participants valued their experiences with their science partners, not all felt well supported and some felt that their science partners had limited availability. In addition, co-chairing experiences were not positive for everyone.



DOTMOCRACY – CCRC RATINGS

In terms of both plenary presentations and concurrent sessions, participants tended to prefer more accessible presentations. This is consistent with the findings from the 2017 program.

Respondents (n=18) ranked their top three plenary presentations as follows:

Session	Presentation title and presenter	Number of votes
P1	Exploring approaches to rational combination immunotherapies - Dr. Pamela Ohashi	3
	Implementation of Canadian made CAR-T cells in Clinical Trial: Experience from the CLIC-01 trial - Dr. Natasha Kekre	9
	Novel Cancer Immunotherapy through a health economics perspective: Designed for value or valued for design? - Dr. Jeffrey Hoch	11
P2	Testing for cancer genetic susceptibility: tides of change - Dr. Clare Turnbull	8
	Genetic Testing at Time of Breast Cancer Diagnosis: Clinical Implications and Patient Perspectives - Dr. Kelly Metcalfe	7
	Functional analysis of missense mutations in homologous recombination proteins - Dr. Jean-Yves Masson	0
P3	Global cancer burden and research priorities in cancer prevention - Dr. Elisabete Weiderpass	8
	Enabling combinatorial cancer immunotherapy clinical trials - Dr. Tania Bubela	2
	Introducing the Canadian Cancer Research Vision - Dr. Stephen Robbins	6

Figure 9. Sunday's breakfast with PIP Supporters, patient partners and science partners.

Although participants were free to attend the concurrent sessions of their choice (the exception being the sessions that they were directly involved in), we asked them to rank the concurrent sessions. The top ranked concurrent sessions were: B4 (9 respondents indicated this as one of their top 3 sessions); E3 (6 respondents indicated this as one of their top 3 sessions); D5 (5 respondents indicated this as one of their top 3 sessions); and E4 (4 respondents indicated this as one of their top 3 sessions).

A1 – Innovations in Cancer Proteomics	**A2** – The Impact of Primary and Metastatic Tumour Microenvironments on Cancer Growth and Response to Therapy	**A3** – Pediatric Oncology: A new frontier - navigating the opportunities and ethical challenges of precision medicine	**A4** – Prevention: Enriching Knowledge by Addressing Time	**A5** – Indigenous Populations and Cancer	
B1 – Imaging and Metabolic Profiling of Cancer	**B2** – Innovations in Cancer Care	**B3** – Integrating Elements of a Palliative Care Approach	**B4** – Stakeholder and Patient Engagement in Clinical Trials and Patient-Oriented Research	**B5** – Hot Topics in Occupational Cancer Prevention in Canada	**B6** – Metastasis
C1 – Model Systems in Cancer Research	**C2** – Cancer Stem Cells and Cellular Plasticity	**C3** – Understanding the Fundamental Basis of Cancer Through the Study of Rare Tumours	**C4** – Getting Real: The Expanding Role of Real-World Evidence (RWE) in Oncology	**C5** – Cancer Prevention and Screening: Selected Updates	
D1 – Microbiome	**D2** – Lessons from Aging	**D3** – Poor Survival Cancers	**D4** – Tackling Inequity in Cancer Care	**D5** – Cannabis, Vaping and E-cigarettes: Canada's Evolving Drug Market and Implications for Cancer Control	
E1 – Mechanisms of Cancer Resistance	**E2** – Cancer Immunotherapy	**E3** – Meeting Healthcare Needs in the 'Era of Cancer Survivorship'	**E4** – Accelerating Clinical Trials in a Genomic-driven Era	**E5** – Consortium Based Research	

Figure 10. Dr. Vera Samarkina, Patient Partner, co-chairing the concurrent session on cannabis and vaping.

GROUP DEBRIEF & POST-PROGRAM FEEDBACK

Nineteen participants provided feedback in the group debrief held after the conclusion of the CCRC. In addition, phone contacts were made with all 20 PIP participants five to six weeks post-CCRC. Participants expressed a high level of motivation to bring what they learned to their current advocacy efforts and to look for opportunities to apply what they learned. Some felt that they gained clarity on how they could contribute to research efforts, local and provincial platforms on a go-forward.

Observations and suggestions for program improvements are consolidated in the table starting on the following page.

Figure 11. Ms. Melissa Coombs, Patient Partner, co-chairing the cancer survivorship concurrent session.

Component	Valued	Challenges	Suggested improvements
Participant Networking	• Valued meeting other patients. • Diversity of experience. • A "nurturing group." • "Exchanging ideas and experiences is powerful." • "I thoroughly benefitted from meeting my fellow PIPs. Each is awe-inspiring and I am better for having met them."	• Lack of time for networking with other patient partners – "more interaction/networking with other patients would have been invigorating – don't need to have the same cancer."	• PIPs to connect before ECI event - Friday evening bonding session with PIPs; meet just patient partners @ 4:00 pm on Friday; ensure PIPs meet as a group before going to ECI. • Organize informal dinner on Monday evening; incorporate more social opportunities. • Post-program: ongoing emails/contact are valuable. • Establish an online patient community; caveat – not an 'advice' forum.
ECI Networking Meeting	• Enjoyed hearing from everyone. • "Fun fact" great element. • Pleasantly surprised at how eager the young researchers were to meet patients.	• Hard to see each other (dark; crowded). • Difficult to hear and converse. • Too much standing/lack of seating. • Not a full dinner, which was unexpected. • Did not understand the purpose of this event.	• Provide smaller icebreakers or speed-dating format or mix and mingle at tables; change ECI to meet and greet with round tables matched by field of interest. Could be rotational with agenda of questions. • Meet science partners beforehand; provide a brief bio of investigators a priori. • Share what's happening in different provinces. • Is the ECI networking event the appropriate venue for connecting with patients? Is there an opportunity to connect on Saturday with ECI?
Webinars	• Webinars/ recordings (YouTube) very helpful, valued and needed.	• Intro webinar not useful – too far in advance; didn't remember each other by the time the program commenced. "Face-to-face interaction is best – that's where relationship building happens."[5]	• Receive acronyms beforehand and better integrate this information. • Pre-post questions for webinar to help focus on important concepts/issues. • Offer earlier vs offer closer to CCRC (difference of opinion on optimal timing). • Share webinars and other resources more broadly.
PIP Curriculum	• Patient resume very valued session. Useful for clarifying your priorities.	• Panel did not allow sufficient time for questions/discussion. • Lunch session with Robin too much; overload. • Need to think about balance and pace – very full days; no time to digest.	• Provide handouts/PPT decks to facilitate notetaking. • Incorporate a break within the PIP curriculum. • Refrain from scheduling talks during meal breaks. • Patient resume –– more materials to participants beforehand (a questionnaire) to help you to formulate your vision/priorities as a research advocate.
Co-chairing	• Questions asked of and answered by patients were valued. • Patients had an opportunity to express their appreciation to the research community. • Felt very valued/respected in concurrent session - "Honoured by respect shown to me."	• Co-chair was not open to connecting beforehand. • Only met with co-chair a few minutes before the session – "very stressful and not a good experience." • Co-chair was dismissive.	• Clearly communicate co-chairing expectations – roles and scope for both patient and science co-chairs. More structure on what co-chairing involves. Guidelines for both individuals so on same wavelength; more standardization. • Ensure/enable co-chairs to connect before CCRC – a conference call or in-person meeting is absolutely necessary. • Create culture shift – "co-chairing is an expectation and not an option." • Ensure all patient co-chairs have an opportunity to present something commensurate with their comfort level.

[5]A pre-program webinar was organized to allow all participants an opportunity to introduce themselves to others. This was held in mid-August 2019.

Component	Valued	Challenges	Suggested improvements
	• "Co-chairing was a great experience — first time actually working directly with a researcher."		• Science co-chairs can help to mentor patient co-chairs on their presentations and vice-versa. • Introduce the "language of respect" see https://twitter.com/tmprowell/status/1197543809594351616?s=20. • Provide guidance to speakers on what is appropriate for a lay summary slide.
Science partners	• 2 patient partners to 1 science partner was a good ratio. • "Felt scientific partners and co-chair were converted on the value of patient involvement"		• More information about science partners sent beforehand; orientation to science partners. Mini-poster review with science partners to understand their work. • 1:1 ratio of science partner to patient partner – could connect beforehand and easier to engage afterwards as well. • Need more than 1 researcher attached to a patient. • Send formal letter to department head of science partners so that participation is recognized in their academic dossier
CCRC-PIP Integration			• Provide highlights of the program each day with key concepts identified - this daily overview could happen during breakfast. • Day-at-a-glance needed – where you need to be for breakfast and lunch times. This should be provided in advance as it would help with booking flights. • Add a concurrent session on patient involvement in research • Provide some mechanism to inform other conference delegates about what PIPs are doing in their communities; sharing information on how patients have made a difference in their province. • Prepare patient partner business cards with names/emails. • Establish a patient feedback service: patient participants to provide feedback on research proposals. • Erect a table in the exhibit hall staffed by scientists/trainees where patients who are not part of PIP can go with their questions.
Posters	• Curated list of posters very useful and appropriate to interests.	• Dark in poster area – difficult to see. • Confusion between abstract and poster number. • Researchers were not at their posters. • Posters daunting for those who have not had any exposure. • Not enough time. • Hard to find posters on curated list. • Could have created own poster list.	• Ensure poster presenters are instructed to be at their posters for some window of time (set up dates in advance). • Have science partners go through a selection of posters with them (10-minute orientation) – see https://thestormriders.org/GRASP/. • Patient partners to tell researchers about themselves – formalized with centrally located posters; patient stories/posters in the centre of the poster hall for patient partners who are interested (not compulsory). CIHR ICR may support the cost of monitors/IT equipment. • Coach scientists on speaking in lay language; communicating via storytelling. • Circulate the types of questions that patients may ask beforehand to poster presenters so that they can be better prepared; could also put these questions in a curated list.

Component	Valued	Challenges	Suggested improvements
Sponsor breakfast			• Provide information on how to engage with your sponsor. • Provide distinct lanyards for science partners and supporters.
Conference app	• Liked contacts.	• Didn't work on Androids. • Cumbersome and not user-friendly.	• Need a better designed/workable app. • Make available earlier – e.g., one week in advance. • Incorporate PIP agenda reminders through the calendar App.
Logistics	• Appreciated designated room for PIP – helped establish an environment to create connection with others.	• Too many emails to track – receiving emails from CCRC, PIP, and ECI. • Room set-up in concurrent sessions – hard to hear people when they are looking backwards at the slides.	• Post delegate arrival times so can participate in cab sharing and initiate networking; bulletin board for early arrivers so that they can connect/touch base with each other. • Offer babysitting (see ASCO). • Provide snacks to get through the morning – especially if participants have dietary restrictions • Better information of PIP-CCRC integration re: scheduling – one central place to obtain this info with visual cues on what to expect each day. • Diverse opinions on PIP program size: increase program size to 22-25 - larger size allows you to hear more perspectives; prefer smaller size as more bonding; 20 was a good size. • Have smudging take place before conference starts in separate room so that asthmatics in audience are not affected and more people can participate. • Make available an 'elder's room' (quiet room) where conference delegates could go and speak with the elder.
Patient involvement in conference planning	• Participation on SPC was a very good experience. Appreciated understanding logistical planning and what is involved when adjudicating posters.		• Involvement of patients on LOC is critical – including 2-3 local patients may help promote and increase visibility of patients at the conference.
Patients not part of PIP			• Prepare distinct lanyards to help them connect with the PIPs. • Reduce registration fees for patient delegates who are not part of PIP. • Invite them to attend lunch with PIP participants on Sunday so they can connect early on.
Repeat attendance	• Take-aways different from first to second program – "wasn't scared to be visible"; gained a lot in the second year. • Second time around you know what to expect. • Easier to select concurrent sessions and get what needed out of the conference. • Would like to go to PIP again – "feel I could contribute more the second time around."		• Consider buddying up previous PIP participants with new participants; repeaters could help orient new participants and give an overview of the co-chairing experience. • Former participants could be PIP mentors. • 2x probably a good cap for PIP participation. • Roles for former patient partners: help with co-chairing readiness, registration and onsite room monitoring.

Science partners also provided feedback either via a phone conversation or email. They were asked to comment on three areas: recruitment of science partners, ratio of science partners to patient partners, and poster sessions. Their feedback is summarized in the table below.

Area	Feedback	Suggestions
Recruitment of science partners	• Details arrived too late – didn't know how it was going to go. • Didn't understand requirements; more information needed. • Lots of emails about the same event – PIP, CCRC and ECI. • "Happy to participate again – patient involvement made conference attendance worth it."	• Connect with people early on. • Add link or paragraph about PIP at point of abstract submission. • Add information about PIP with ECI communications to help promote/foster support. • Identify benefits – bullet points. • Pre-conference promotion of the program - share testimonials from previous years or some of the powerful stories from patients to help in recruitment; incorporate quotes on importance and benefits. • Provide an info-graphic about PIP – could mention that granting agencies are increasingly requiring patients to be involved in research. • Don't limit to ECI; promote to ECI and go outside for quota; look to include senior post-docs beyond the ECI; email all senior postdocs registered for the conference and ask them to submit an application to be a science partner. • Engage trainees to be paired along with patients and science partners. • Look at involving mid-career scientists as partners.
Ratio of science partners to patient partners	• 3 to 1 difficult to juggle as patients wanted to attend different sessions • "The 2:1 ratio was perfect and completely doable." • "Being a science partner was the best part of the conference." • Liked 2:1 ratio – "nice dialogue that happened"; patients could learn from one another. • Patients had different interests so spent more time with one than another. • Felt that I didn't have biomedical background to support patients technically. • It is a time commitment and it is more difficult to network if you are part of PIP.	• Look at a 1:1 ratio to allow for more in-depth conversations and tailoring. • Not all science partners are experts in all areas of cancer research. Make more explicit that not an expert in all areas. • Prepare poster with science partner pictures and expertise as visual reminder to patient partners (science partner bios could also be included in the conference app). • Do Q&A with science partners in the form of a panel during PIP breakfasts so that patient partners can ask questions about the sessions that they attended and benefit from the expertise of all science partners.
Posters	• "The poster session was challenging even for us scientists…too many posters for such a short poster session." • Not everyone is prepared to deliver a lay-friendly poster presentation.	• Provide some honour/recognition for poster presenters who have made a patient-friendly poster presentation. • Science partners to lead guided science walk – set-up times with partners to go and look at posters – could do in lieu of a concurrent session; a quieter time/designated time for posters – set-up sessions with poster presenters. • Inform poster presenters on curated lists that specific patients will attend their posters – perhaps times could be set up for them to meet and review the poster; science partners to visit top 3-5 posters together with patient partners. • Provide a webinar/handout on posters – what it is, how typically laid out, types of figures, etc. • Provide an extra row of e-posters that are presented in lay terms. This could be done on a voluntary basis and involve more than just the science partners. Volunteers could be solicited at the time of abstract submission – slides might work well as a format. • Add a one-sentence lay summary requirement to poster abstract submissions.

Area	Feedback	Suggestions
		• Promote use of "Better Poster" template – see https://www.insidehighered.com/news/2019/06/24/theres-movement-better-scientific-posters-are-they-really-better.
Other		• Provide a defined area in the back of the meeting rooms so that patient and science partners can talk quietly during the lectures and minimize disruption to other attendees. • Incorporate a Q&As with science partners on final day as an open forum to ensure that any outstanding questions are answered. • Understand patient interests ahead of time; could switch up and sit with different partners.

Figure 12. From left to right: Mr. Patrick Sullivan, CCRA Award Winner, and Mr. Denis Raymond, member of the 2019 Local Organizing Committee and Patient Advocate (PIP 2017).

CCRC DELEGATE ONLINE SURVEY

A total of 320 CCRC delegates (36%) completed the post-conference online survey. Over half (53%) felt that the conference objective related to patient involvement was mostly achieved (Figure 13). This is much higher than the 33% of respondents in 2017. Familiarity with including patients/caregivers as partners in research (Figure 14) and interest in involving patients/caregivers in research (Figure 15) was highest in the 'other' group (consisting of delegates from the charitable sectors and industry as well as patient advisors) and lowest among trainees, although there does seem to be positive change on these two indicators since the 2017 program (Figure 16). There were at least 133 contacts made between delegates and patients during the CCRC (no data available for 2017) (Figure 17).

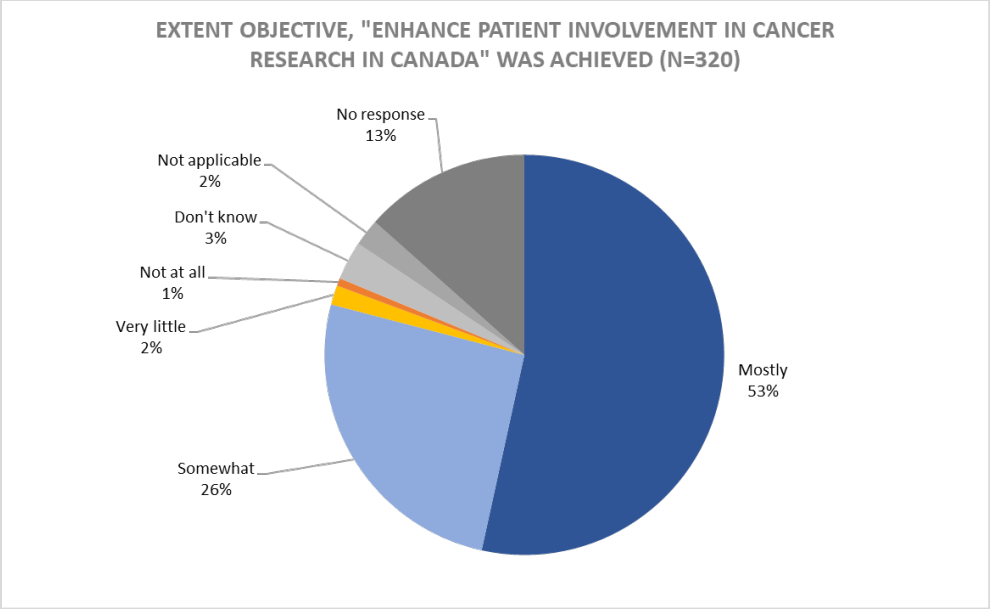


Figure 13. Achievement of conference objective related to patient involvement.

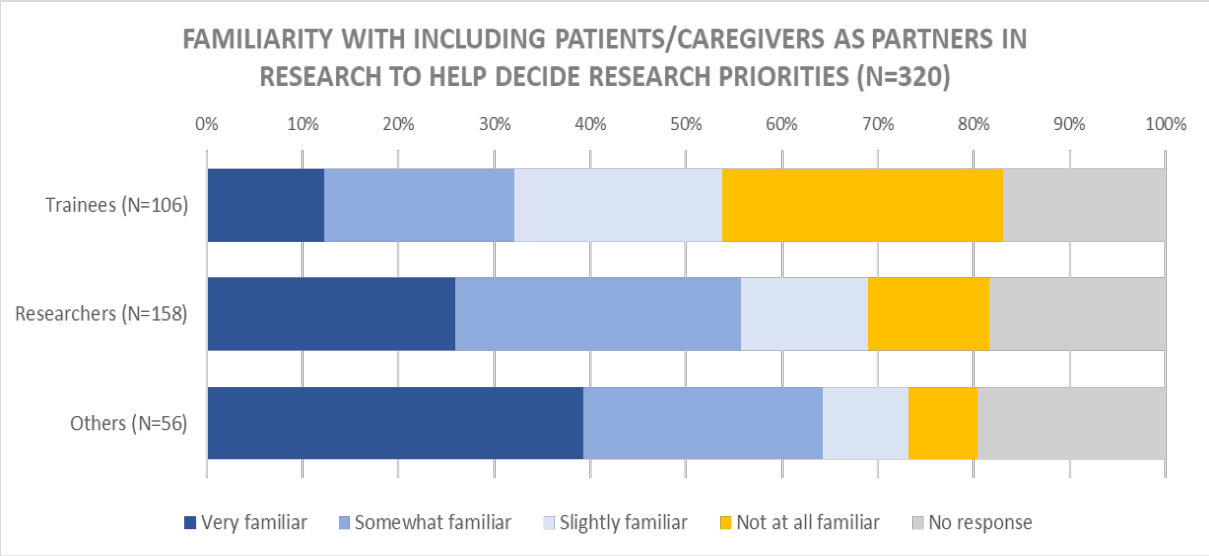


Figure 14. Familiarity with patient involvement in cancer research.

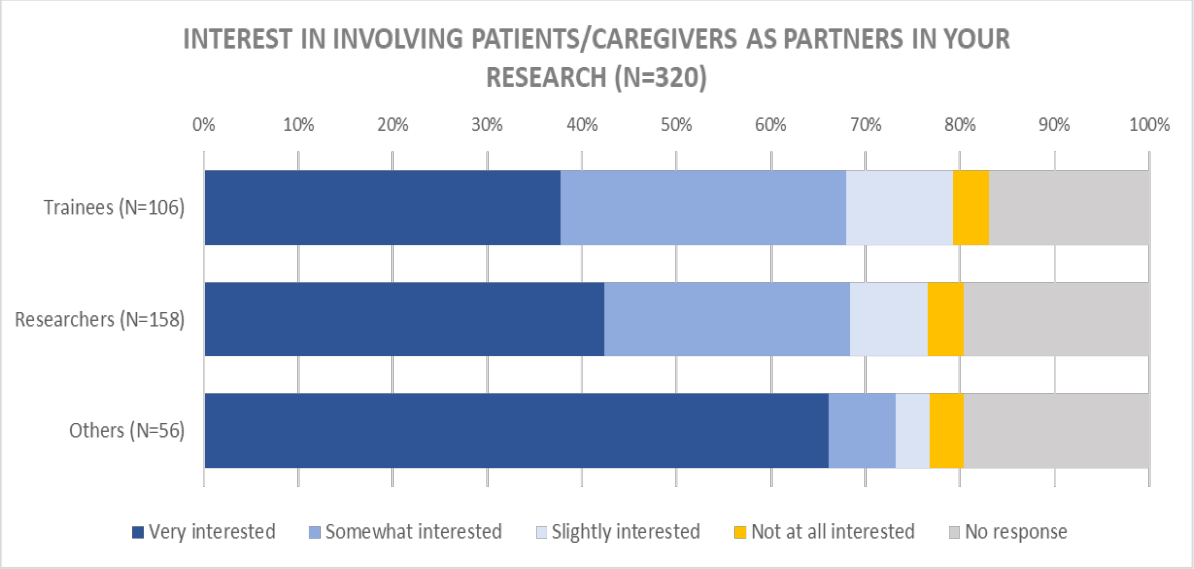
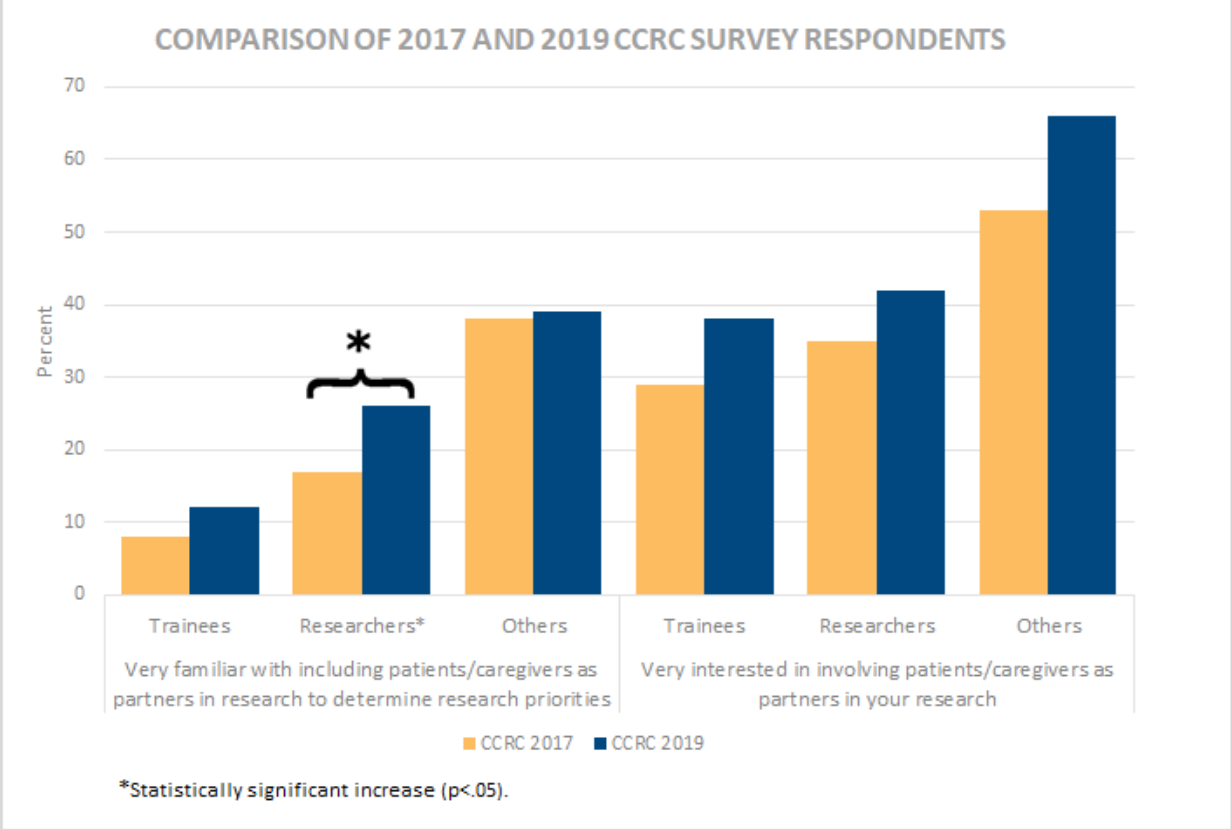


Figure 15. Interest in patient involvement in cancer research.



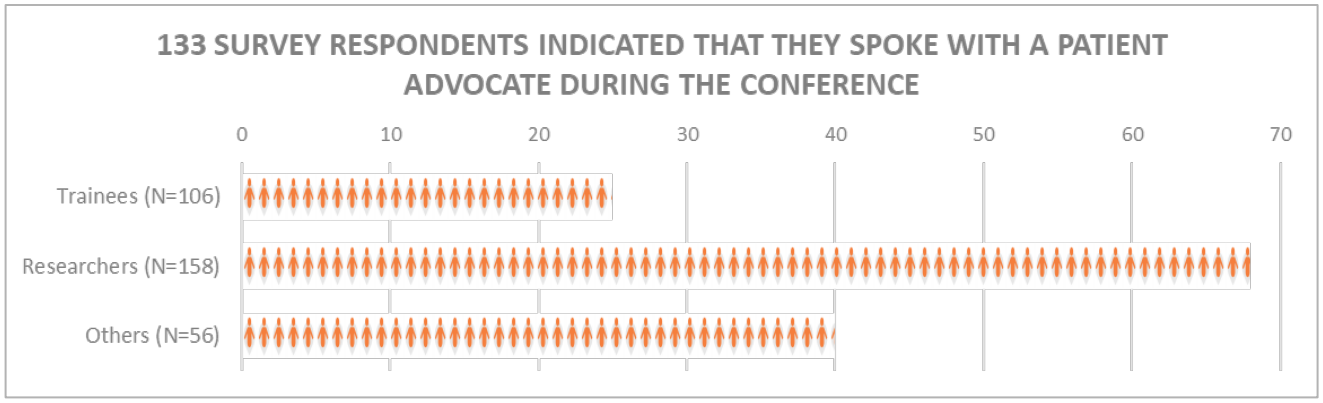
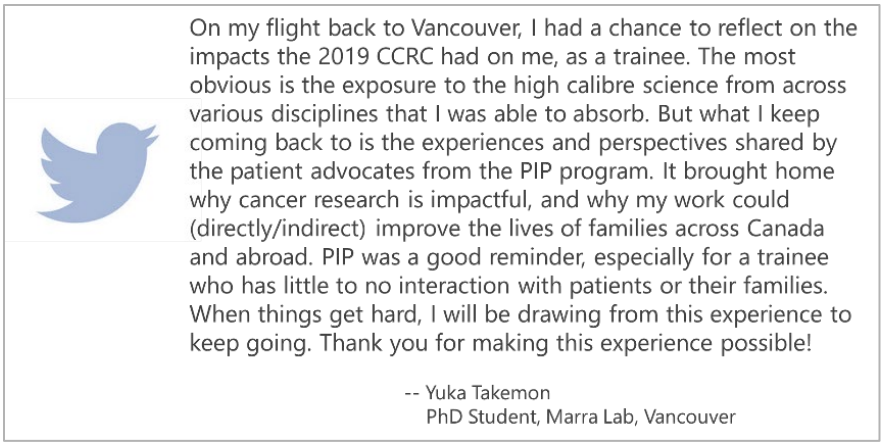


Figure 17. Number of respondents indicating that they had spoken with a patient advocate.

Some of the open-ended comments from the survey specifically identified the involvement of patient advocates as an important component of CCRC and these are a testament to the mutual benefits of PIP.

- "The integration of patient advocates was hugely valuable and added more depth to what I learned while at the conference."
- "…the greatest parts were…patient involvement, which really encouraged me to keep going regardless of the hard work at the lab and the bad days, since it means a lot to many people, means hope for them."
- "I really enjoyed having the patient advocates as co-chairs at the sessions. I don't work directly with patients; only receive patient samples and I appreciated hearing the back stories from them. Thank you for including their voices and stories."
- "Enjoyed the patient advisors attending the sessions and being part of panels as speakers - would love to see that continued as well."
- "PIP program so important and appreciated."
- "I loved the inclusion of patient perspectives as part of the concurrent sessions. A great way to help put the presentations in context."



PROGRAM REVENUE & COSTS

For 2019, costs exceeded revenues by $6,207.07. Original budget projections were based on lower meal and accommodation costs. Meal costs were 35% higher per person than in 2017 (not adjusting for inflation). Accommodation represented 42% of the 2019 cost; this was 30% in 2017. Financial sustainability is greatly dependent on accommodation and food costs and these are challenging to control in a conference centre setting where catering costs are typically quite high to offset low room rental rates.

Revenue

Source*	$	Participants supported (N)**
Alberta Cancer Foundation	9,000	3
Canadian Partnership Against Cancer	9,000	3
Cancer Cancer Society	6,000	2
Fonds de recherche du Québec – Santé	6,000	2
The Terry Fox Research Institute	6,000	2
BioCanRx	3,000	1
C^{17} Research Network	3,000	1
Cancer Research Society	3,000	1
Ovarian Cancer Canada	3,000	1
Prostate Cancer Canada	3,000	1
Saskatchewan Cancer Agency	3,000	1
TOTAL	**54,000**	

**CIHR ICR supported 8 science partners, who were recruited from ECI program. Estimated support provided was $22,800 (8@$2,600 + 20@$100).*

***Two participants were supported through the main conference budget as they were members of the CCRC organizing committees.*

Category	$	NOTES
Travel	7,338.39	Lower than anticipated as 4 participants were from the Ottawa-Montréal area.
Accommodation	25,494.82	PIP participants were housed at the primary conference hotel adjacent to the conference centre to facilitate access to the meeting venue.
Meals and other related conference expenses (PIP room rental, AV and per delegate CCRC fee)	17,693,92	
Other incidental expenses incurred by participants (ground transportation, meals outside those provided by the conference, other incidentals)	9,679.94	Includes additional dinner on Friday not accounted for in original projections.
TOTAL	**60,207.07**	

Although it is anticipated that hotel costs for the 2021 CCRC in Halifax will be lower, travel costs may be higher if broad geographic representation is to be maintained. Initial projections for a 24-participant PIP program in 2021 suggest that an increased supportership rate of $3,500 per participant

would ensure a revenue-neutral outcome. An alternative funding model – sponsoring the program as opposed to a specific individual – will be explored.

PROPOSED RECOMMENDATIONS

Key Lessons Learned

- Build in more 'down time' for participants; be cognizant of physical limitations and the need for time to digest information being presented.
- Allow for more participant networking – this may be even more important if a larger number of participants is approved for the 2021 program.
- Re-tool poster sessions.[6] A multi-pronged solution is likely needed and decisions made by the CCRC will help dictate the possibilities of how PIP participants can interact/interface.
- Provide more clarity and preparation on co-chairing for both science and patient co-chairs. There may be a role for former PIP participants to help in this area.
- Engage in earlier (spring 2021) planning with CIHR ICR on the ECI meeting and improve, streamline and consolidate pre-program logistics and communications. An integrated communications strategy is needed for PIP, CCRC, and the ECI meeting.
- Look at ways to augment science partner support. Science partners recruited from CIHR ICR ECI went quite well for a first go, but there is room for improvement in terms of communication and a need to look at whether/how the budget can support more science partners.

Figure 18. Ms. Debra Walker, Patient Partner, interacting with an exhibitor at the community event.

Next Steps

Patient and science partners offered a range of suggested improvements. All are important and will be considered within the lens of available human resources and budget. A working group consisting of program sponsors, PIP participants and the CCRC lead will be convened in the fall of 2020 and program improvements will be vetted by this group.

In addition to these suggestions, it is also proposed that SPC members become more directly engaged in PIP. Attending the PIP breakfast sessions, for

[6]Concerns about the poster sessions were not unique to PIP participants. There will be a larger effort to re-design the poster sessions within the larger CCRC planning process.

example, may be a valuable way to introduce and highlight key themes for each day of the scientific program to PIP participants and help broaden their exposure to different researchers.

Participants would like more lay-friendly cancer science/research information. Plans are already underway to boost the CCRA website in this regard.

The call for an online community of patient partners was raised in 2017 as well. The feasibility of doing this within the Canadian Partnership Against Cancer through MS Teams is currently being explored and it is hoped that something will be in place in 2020. This vehicle may be helpful in addressing some of the communication issues identified by participants.

An awards mechanism to recognize lay-friendly, patient accessible posters should be investigated. Perhaps this can be introduced in a staged process. Several of the suggestions related to e-posters in the previous section may be relevant in this regard.

The feasibility of a PIP concurrent session (also a mechanism to introduce more downtime) needs to be explored in the earliest phases of CCRC scientific program planning.

An increased per participant supportership rate or movement to a program sponsorship model needs to be vetted with existing and prospective sponsors. Additionally, the feasibility of augmenting the number of science partners participating in PIP through either the ECI or through invited speakers needs to be explored.

PIP 2019 SPONSORS

APPENDIX A.

Blog posted to: https://rethinkbreastcancer.com/why-i-get-involved-in-cancer-research/

WHY I GET INVOLVED IN CANCER RESEARCH
By Nathalie Baudais December 12, 2019

Attending the Canadian Cancer Research Conference (CCRC) in Ottawa reinvigorated my interest in cancer research advocacy, which let's face it, can be a complicated space. Here's my experience and why I get involved in cancer research and why patient advocates are needed in this area.

SHARING MY STORY
Alongside other patient advocates, I had the opportunity to co-chair sessions, allowing us to share our stories and set the tone for the other speakers. It reminded the speakers of the importance of relating their research findings to patients.

I also had the opportunity to be a part of the Scientific Planning Committee for the CCRC, which allowed me to be involved in the development of the scientific program to bring a patient's perspective to the sessions. I also reviewed some of the abstract submissions to score them for a poster presentation or an oral presentation.

The conference allowed me to meet so many people! I spoke with researchers who are committed to improving cancer treatments and who are interested in involving patients as part of their research team, health professionals involved in clinical trials who make clinical decisions for their patients and patient advocates who are dedicated to improving the lives of patients by bringing a patient's perspective to cancer research and changing health policy.

I acknowledge that research work is a long process and it can often involve a series of dead-ends. It can be demoralizing for researchers to face this arduous work on a daily basis. Speaking with patients can remind them of the importance of their work and motivate them to persist despite the challenges.

GAINING KNOWLEDGE
The CCRC has a Patient Involvement Program, which provides patients with education opportunities prior to, and at the conference. Patients learn a bit about basic biology, immunotherapy, etc. so that they can better understand the work that will be presented at the conference. The Patient Involvement Program also has patient-specific sessions to help patients become better advocates, which is very helpful!

Attending the conference allowed me to learn about the latest advances in cancer research. Here are some key learnings that really stood out:

The microbiome may be linked to therapy response. There is ongoing research to determine whether the gut microbiome can be modified to improve a patient's response to treatment, perhaps by combining prebiotics with immunotherapy treatments.

Completing genetic testing (multigene panel) on all breast cancer patients would be impactful but is currently economically unfeasible, due to the resources required for genetics counselling. The current criteria used to

screen patients for genetic testing is resulting in missing women with mutations that could be targeted by existing treatments. Researchers are looking at ways to expand the current genetic testing approach without overburdening the health care system. New models of care are needed.

Researchers in Montreal (in collaboration with MBC patient, Laurie Hendren) have developed a patient empowerment app. The app allows patients to access their medical information, check-in for appointments, reminds them if any special preparation is needed prior to their appointment, share their data for research purposes, etc. They continue to develop the functionality of the app and are expanding it to multiple medical centres in the Montreal area. I hope that it will eventually become available nation-wide.

Researchers in Calgary are using the POET approach to precision oncology. POET – precision oncology experimental therapeutics. They will be monitoring 500 patients in real-time to learn how to get the right drug to the right person at the right time and right place.

Researchers are studying epigenetics to determine whether they can predict chemo resistance (regardless of the line of treatment) based on epigenetic variants.

Canadian cancer research is grouped into these four pillars:

- Biomedical Research – the goal of understanding normal and abnormal human functioning, at the molecular, cellular, organ system and whole body levels.
- Clinical Research – the goal of improving the diagnosis, and treatment of disease and injury; improving the health and quality of life of individuals as they pass through normal life stages.
- Health Services Research – the goal of improving the efficiency and effectiveness of health professionals and the health care system, through changes to practice and policy.
- Social, Cultural, Environmental, and Population Health Research – the goal of improving the health of the Canadian population, or of defined sub-populations, through a better understanding of the ways in which social, cultural, environmental, occupational and economic factors determine health status

With everything that I learned at the conference and seeing the breadth and scope of ongoing cancer research, I remain hopeful that patients will be offered better treatments, have better treatment outcomes, improved quality of life, and maybe even, one day, we'll have a cure for cancer.

Online article at https://publications.mcgill.ca/medenews/2019/11/12/mcgill-researcher-shares-2019-ccrc-experience/
Posted: November 11, 2019
MCGILL RESEARCHER SHARES 2019 CCRC EXPERIENCE

The 5th Canadian Cancer Research Conference (CCRC) organized by the Canadian Cancer Research Alliance (CCRA) took place from November 3 to 5 at the Shaw Centre in Ottawa. A meeting with almost 1000 participants, the CCRC served as a platform for new scientific research and was attended by scientists, clinicians, trainees as well as patients, caregivers and patient advocates. With 600 posters, four plenary sessions, and over 100 breakout talks, participants had the opportunity to learn about Canada's finest research in cancer, with themes ranging from immunotherapy, aging, cancer stem cells, proteomics, and clinical trial developments.

Dr. Julia V Burnier, a newly recruited researcher at the Research Institute of the McGill University Health Centre , and Assistant Professor in the Departments of Oncology and Pathology at McGill University's Faculty of Medicine, was awarded a CIHR-OICR award to participate in the CCRC as well as in the Early Career Investigator (ECI) meeting, funded by the CIHR, OICR and Prostate Canada. The ECI meeting, held before the CCRC, included over 50 young scientists from across Canada. Included in the program were talks from established scientists who gave advice on how to build a lab and program. Participants also heard from patients and patient advocates who spoke of their experience and outlook on the future of cancer research. "It was an eye-opening experience to hear patients and advocates speak about what research means to them," says Dr. Burnier. "Science is their hope, whether for their own disease or for the future generation of patients. It was humbling but also inspiring and it made me realize just how important our work is."

The CCRC conference provided three more days filled with excellent scientific talks, dedicated time for networking and social events. However, according to Dr. Burnier, the highlight of the meeting was not just the science or networking, but rather another patient-centric program. "I was given the privilege to participate in the Patient Involvement in Cancer Research Program (PIP), which paired patients and patient advocates with scholars during the CCRC meeting."

Supported by the Fonds du Recherche en Santé du Quebec (represented at the meeting by Dr. Anne-Marie Mes-Masson from the Centre hospitalier de l'Université de Montréal (CHUM)), each scholar was paired with 1-2 patients during the 3-day conference to explain the science of what they would be hearing during the conference. When asked why patient involvement is important. Dr. Mes-Masson said "We would be the only industry to not consult with the end user before using a product. One of the biggest advantages they bring is an experience that we as scientists don't have and they challenge us to think differently about each scientific problem."

Dr. Burnier was paired with Ms. Sylvie Halde and Ms. Lucie Piché, two cancer survivors who have dedicated much of their time to being advocates for patient involvement in cancer research. Both Ms. Halde and Ms. Piché co-chaired different sessions during the conference.

Sylvie Halde is a lawyer in maritime law and works for the Department of Justice Canada. She is a survivor of ovarian cancer, which was discovered by chance 11 years ago at an early stage while trying to have a family. "I am here because ovarian cancer is a silent killer and not enough woman survive long enough to speak to it, as a grateful survivor and ex-participant in a clinical research, I have to give back. For patients, researchers and their researches mean HOPE and as the patients are the ultimate beneficiary, it is important that a two-ways dialogue be established. The increase of patient participation in clinical trials is one of the goals of my attendance at the conference," she explains. "This said, doctors and researchers need to be more convincing in their approach in order to get the most patients participating in their trials. As well, patients should feel that there are real benefits for them to participate and that their participation will enhance their health care and the health care of next generation. The more patients participate, stronger are the trials, better are the advancements of science."

Lucie Piché spent 30 years building her career in the field of communications, as a journalist, in press relations, as a manager, and as a strategic consultant. As a two-time survivor of breast cancer (2004 and 2013), she has become involved in many types of activities to help improve patient care. Since 2005, in addition to organizing and participating (with the Institut du cancer de Montréal), in a number of fundraising activities for research on gynecologic cancers, she was recruited as a Patient Partner by the CHUM and invited to become a member of

multiple panels, projects and committees dedicated to improving patient care. In 2013, she became the first to be recruited in the Patient Partnership Program of the Faculty of Medicine at Université de Montréal. Since then, she has served as assistant teacher and mentor for medical students, as well as a coach for other patients. The goal of this program is to convey the patient experience to health care providers, in an effort to help transform the healthcare process.

"Throughout all the activities that I have been involved with, my goal has been to act as the voice of other patients, to help improve the health care system, to provide the best care, to develop tools to raise money for cancer research, and to bring awareness for the importance of funding research for cancer. As an active Patient Partner, I try to become a partner in co-building health care, research and education."

Dr. Burnier says, "This is not an experience I will forget. Patient advocates can be a powerful partner in research and we can gain a lot from them. They've taken a devastating experience and turned it into something positive."

Beyond the serious topics of the weekend conference, Dr. Burnier notes that there was much fun and laughter shared. "It was a pleasure to get to know Lucie and Sylvie, as well as the other patients and scientist partners. We all quickly became friends, and at the end of the day we are all working towards a common goal – better and more effective treatment for cancer patients, and hopefully a cure one day".

The next CCRC conference will be held in Halifax in November 2021 and will again have a focus on patient advocacy.