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 2023 Hybrid PIP and Recommendations for the 2025 PIP

2024-Mar-27

CONTENTS

ACKNOWLEDGEMENTS

The 2023 Hybrid PIP was made possible by the financial support of the Alberta Cancer Foundation, Brain Tumour Foundation of Canada, Canadian Cancer Society, Canadian Partnership Against Cancer, Cancer Research Society, CIHR Institute of Cancer Research, FRQS Oncopole/Quebec Cancer Research Network (RRCancer), Garron Family Cancer Centre/The Hospital for Sick Children, Leukemia & Lymphoma Society of Canada, Ontario Institute for Cancer Research (OICR), and The Terry Fox Research Institute.

We would also like to acknowledge the patient partners who comprised this year's working group and whose leadership helped shape the 2023 program: Dr. Don Desserud (Chair), Ruth Ackerman, Melissa Coombs, and Dr. Rosilene Kraft. Don and Melissa led the in-person component of the program while Ruth and Rosilene led the virtual component.

In-person participants helped to plan and deliver a community event held on November 11th. In addition to Don and Melissa, the in-person group included: Isabelle Allain-Labelle, Jennifer Coish, Barry Darby, Judy Donovan Whitty, Anita Hamilton, Nicole Lee, Dr. Cara MacInnis, Pauline McIntyre, Carol Pierre, Wayne Olford, and Sheryl Raeburn Olsson.

The virtual participants were engaged in the adjudication of the 2023 PIP Grant Competition. In addition to Ruth and Rosilene, they included: John Corriveau, Howard Dellar, Sandra Dudych, Kirsten Efremov, Darren Frew, Shantelle Gould, Mark Haan, Karen Haas, Harjeet Kaur, Kathleen L'Abbée, Lucie Lacombe, Dr. John Mark, Christine McKay, Megan Emily Quintal, Anni Rychtera, Lorena Seggie, Sundas Shamshad, Vivian Simbul Sim, Cathy Smallwood, Michelle Stratton, and Chantale Thurston. The active participation of the patient partners is what makes PIP, PIP!

Thirty-one science partner volunteers helped to support patient partners to understand the science being presented during the CCRC, with a few supporting more than one patient partner. They were: Drs. Taha Azad (Université de Sherbrooke), Julia Burnier (McGill University), Dean Chamberlain (Saskatchewan Cancer Agency), Sonia del Rincon (McGill University), Britt Drögemöller (University of Manitoba), Lynn Gauthier (Université Laval), Hong Han (McMaster University), Nicholas Jacquelot (University of Calgary), Katrin Julia Kaal (Dalhousie University), Tobias Karakach (Dalhousie University), Jennifer Kwan (Queen's University), Sampath Kumar Loganathan (McGill University), Talía Malagón (McGill University), Arvind Mer (University of Ottawa), Francois Mercier (McGill University), Hassan Mir (Ottawa Heart Institute), Alli Murugesan (University of New Brunswick), Ayman Oweida (Université de Sherbrooke), Samara Perez (McGill University), Sarah Poynter (Wilfred Laurier University), Arlinda Ruco (St. Francis Xavier University), Stacey Santi (Health Sciences North Research Institute), Ambreen Sayani (University of Toronto), Amina Silva (Brock University), Aynharan Sinnarajah (Queen's University), Syam Somasekharan (University of British Columbia), Thomas Velenosi (University of British Columbia), Xian Wang (Queen's University), Sam Workenhe (University of Guelph), Yiwen Xu (BC Cancer), and Michael Yan (University of Toronto).

In addition, the following researchers led the plenary and concurrent sessions with PIP participants as co-chairs: Drs. Ali Bashashati (University of British Columbia), Touati Benoukraf (Memorial University of Newfoundland), Jeannette Boudreau (Dalhousie University), Jennifer Brooks (University of Toronto), David Busolo (University of New Brunswick), Harvey Chochinov (University of Manitoba), Sherri Christian (Memorial University of Newfoundland), Sachin Katyal (University of Manitoba), Paola Marcato (Dalhousie University), Michael J. Monument (University of Calgary), J. Patrick Murphy

(University of Prince Edward Island), Rachel Murphy (BC Cancer Research Centre, University of British Columbia), Bertrand Routy (Centre de recherche CHUM (CRCHUM)/Université de Montréal), Uri Tabori (The Hospital for Sick Children), Robin Urquhart (Dalhousie University), and Franco Vizeacoumar (Saskatchewan Cancer Agency, University of Saskatchewan).

Dr. Louisa Salemi, Specialist, Scientific and International Engagements at the Canadian Partnership Against Cancer, in her leadership role with the CCRC, was critical in enabling the hybrid format of PIP and she worked to ensure that PIP participants were well-profiled at the conference, on the conference platform, and in their co-chairing roles. Other pivotal support was provided by staff of the Canadian Partnership Against Cancer: Neda Didani (formerly Administrative Assistant, Finance and Corporate Services), who assisted with logistics and shipping; Pauline Walsh, Assistant with Corporate Services, who assisted with travel arrangements and expense claim reimbursements for in-person participants; Kris Atterbury, Specialist, Production and Design, who produced the PIP and PIP grant promotional videos; Jessie Yin, Controller, and Sheila Zhang, Senior Accountant, who managed the in-flow and out-flow of supporter contributions and program expenses; Shirley Dong, Manager, Finance and Partner and Vendor Services and Angela Fong, Contract Analyst, who executed the agreement for the PIP grant; and Florence Bentley, Specialist, French Translation, who supported the program's translation needs, often working under tight timelines.

And finally, the success of PIP is largely due to the perseverance of 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 is fortunate to have the responsibility of administering and coordinating PIP. Should you have any questions or concerns about this report or PIP in general, please follow up with her (kimberly.badovinac@partnershipagainstcancer.ca).

SUMMARY

A decision was made early in the planning process that the 2023 Canadian Cancer Research Conference (CCRC) would be offered in a hybrid format, largely to permit an expanded number of patient partners to participate in PIP. The original plan was to include 40 patient partners – 24 in the virtual component and 16 in the in-person component. With attrition from the original selected participants, there were 36 patient partners as part of PIP – 13 attending in person and 23 attending virtually. This year's program was supported by 11 Canadian Cancer Research Alliance (CCRA) member and affiliated organizations.

Of the 25 participants (69% response rate) completing the post-program evaluation, 88% indicate that the PIP was worth their time to attend. Most participants felt the program had relevance and rated the various components as valuable. Among conference delegates responding to the post-CCRC online survey, there was familiarity and interest in involving patients in cancer research, although the ratings on these indicators were not different from the 2021 program.

Given the success of the initial 2021 PIP grant, the 2023 opportunity was re-tooled based on the feedback received from applicants of the 2021 program. The changes included: restricting the opportunity to post-doctoral/post-degree fellows; strengthening the application in terms of the requirements for identifying the patient engagement component; and changing the application format; lengthening application submission timelines. Despite these changes, only four applications were received (in contrast, 19 applications were received in 2021).

Of note, there was substantial variability in the participant experience among in-person and virtual participants (although the response rate to the post-program survey among virtual participants was low at 52%). Responses from virtual participants indicated that the program was less valuable and there were substantial issues with the virtual platform that impeded the experience (i.e., late deployment so no opportunity for orientation, limited staff resource for real-time interaction, and reduced offering in the virtual program).

Lessons learned from 2023 were much the same as in 2021 – i.e., better preparation of both science partners and session co-chairs is needed to ensure that these program components are optimized, the platform for the virtual posters needs to be better designed to improve patient partner usability and facilitate interactions between poster presenters and PIP participants, and program support needs to be enhanced, especially for a hybrid program.

Given the strong interest in PIP combined with the challenges in offering the hybrid program as designed in 2023, it is recommended that the 2025 program offer an in-person component only. Re-tooling the virtual offering (which means decoupling from the CCRC) and developing a program that offers a more rewarding experience for virtual participants is recommended. Given escalating costs for conference delivery post-COVID, **PIP is not viable without a doubling of support for the program**. Various scenarios are provided at the end of this report with estimated costs for 2025.

BACKGROUND

The history of PIP has been described in past evaluation reports, and readers are invited to consult those documents to access that information.[1]

PIP originated by patient partners and continues to be led by patient partners. It has been an important part of the wider patient engagement efforts in Canada by helping to build capacity and connect patients interested in cancer research.

Patient partners are eligible to attend up to three programs and can elect to stay connected after their program participation in the PIP MS Teams, an online forum that participants of the 2019 PIP recommended be established.

Although we use the word "patient" in the title of PIP, 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.

PROGRAM APPLICANTS AND PARTICIPANTS

The call for participant applications was made earlier than in past years to permit more time for participant engagement prior to the conference. The call was made on January 23, 2023. The program was promoted on the CCRA website and social media channels, through the existing PIP network, and by individual CCRA member organizations. The online application (in both official languages) was prepared in QuestionPro. Applications were due on March 1, 2023.

KEY ABBREVIATIONS

CCRA	Canadian Cancer Research Alliance
CCRC	Canadian Cancer Research Conference
EPC	Executive Planning Committee
SPC	Scientific Program Committee

APPLICANTS

The program was organized to include 40 participants – 24 virtual and 16 in-person, with the latter to be selected from applicants in the four provinces in Eastern Canada. A total of 88 applications were received by the deadline, 36 more than what was received in 2021. It is believed that increased awareness of the importance of patient engagement in research and a growing contingent of patient partners engaged with CCRA member organizations were key contributors to demand for the program.

Of the 88 applicants, most were women (70/88) and over half were in the age range of 50-69 years (47/88). There were applicants from all 10 provinces and one from the Yukon. Many had been diagnosed with breast cancer (45/88); blood cancer (14/88) was the second most frequent diagnosis. Very few were caregivers (8/88) and most rated their research experience in the mid-range – i.e., some familiarity/some involvement in cancer research activities/projects/priority setting (54/88).

Participant selection was a balancing act, designed to optimize the diversity of program participants as well as the needs of organizations supporting the program. Applicant selection was based on numerous factors – geography, gender, age, cancer experience, and research experience (a mix of inexperienced and experienced research advocates is preferred). Forty applications were selected,

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[1] See https://www.ccra-acrc.ca/wp-content/uploads/2020/08/PIP_2019_eval_report_EN.pdf.

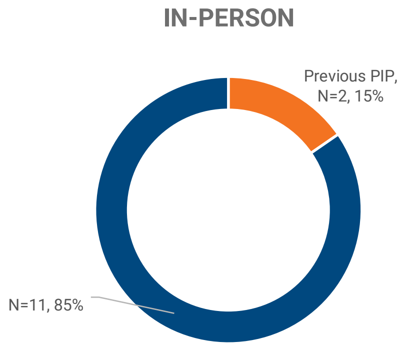
however, four participants opted out for health and personal reasons and, due to time constraints, these vacancies were not filled.

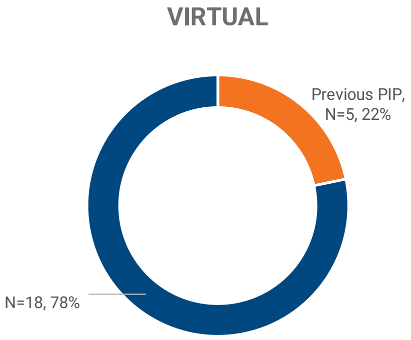
PARTICIPANTS

The following page provides a demographic summary of the 36 participants for 2023 PIP. This was the largest participant cohort to date for PIP. Seven participants had previously attended PIP.

Standing from left to right: Isabelle Allain-Labelle, Angus Pratt (PIP alumnus), Kim Badovinac (coordinator), Barry Darby, Wayne Olford, Anita Hamilton, Melissa Coombs (PIP Working Committee), Don Desserud (Chair, PIP Working Committee), Cara MacInnis, Jennifer Coish, and Carol Pierre. Seated from left to right: Judy Donovan-Whitty, Cathie Hays (PIP alumna), Sheryl Raeburn-Osburn, Pauline McIntyre, Nicole Lee, and Rosilene Kraft (PIP Working Committee).

2023 PIP Participant Snapshot (N=36)





		IN-PERSON	VIRTUAL	TOTAL
Women	35 to 49 years	5	5	**10**
	50 to 69 years	4	12	**16**
	70+yrs	1	1	**2**
Men	35 to 49 years	0	1	**1**
	50 to 69 years	2	3	**5**
	70+yrs	1	1	**2**
	TOTAL	**13**	**23**	**36**

	Perspective		
	IN-PERSON	VIRTUAL	TOTAL
Cancer patient/survivor	12	21	**33**
Caregiver	0	1	**1**
Both	1	1	**2**
TOTAL	**13**	**23**	**36**

	Self-rated experience level		
	IN-PERSON	VIRTUAL	TOTAL
No involvement in cancer research	5	4	**9**
Some familiarity/some involvement	7	17	**24**
Extensive involvement	1	2	**3**
TOTAL	**13**	**23**	**36**

Time Since Initial Diagnosis	Blood	Breast	Colorectal	Prostate	Skin	Other*	TOTAL
Less than 5 years	2	5	1		2	2	**12**
5 to 10 years	4	5	2	2		1	**14**
More than 10 years	2	5		1	1	1	**10**
TOTAL	**8**	**15**	**3**	**3**	**3**	**4**	**36**

**Appendix, Brain, Oral, Ovarian*

		CITY/TOWN SIZE				
		Rural	Small	Medium	Large	TOTAL
IN-PERSON	NB	1	1	1		**3**
	NL		1		3	**4**
	NS	1	3			**4**
	PE		1	1		**2**
VIRTUAL	AB			1	2	**3**
	BC		1	1	2	**4**
	MB				2	**2**
	NL				1	**1**
	ON		2	1	5	**8**
	QC		2		1	**3**
	SK				2	**2**
TOTAL		**2**	**11**	**5**	**18**	**36**

Population Centre Classification*	
Rural	Less than 1,000
Small	1,000 to 29,999
Medium	30,000 to 99,999
Large	100,000+

**Statistics Canada*

PIP COMPONENTS

Working Committee

Like the 2021 PIP, this year's program was directed by a working committee comprised of four patient representatives, all of whom had previously attended PIP. Dr. Don Desserud, patient representative on the CCRA Advisory Board since January 2020 and participant of the 2019 and 2021 PIPs, was the chair. Don along with Melissa Coombs, who also attended the 2019 and 2021 PIPs, were responsible for the in-person component. Ruth Ackerman, patient representative on the CCRA Advisory Board since January 2018 and participant in all PIPs since 2017, along with Dr. Rosilene Kraft, participant in the 2021 PIP, were responsible for the virtual component.

Don and Ruth, given their roles on the CCRA Advisory Board, were also members of the CCRC Executive Planning Committee (EPC), the oversight body for the CCRC. Melissa and Rosilene served on the CCRC Scientific Planning Committee (SPC). The SPC spearheaded the development of scientific content by identifying novel session themes, chairs, and speakers, and overseeing abstract review and selection.

The working committee provided invaluable direction, support, and feedback in terms of the program format and the process and materials related to the PIP grant. In addition, they helped to create videos on PIP, which were aired during the CCRC, helping to inform conference delegates about the program and elevate the patient profile.[2] Ruth helped with the creation of the promotional video on the PIP grant with the grantee, Dr. Nawal Amhis.[3]

In terms of the CCRC itself, all four members were co-chairs for the four plenary sessions at the CCRC.

Program Components

The in-person and virtual components are outlined below. The experiential opportunity for the in-person participants was the planning and delivery of the community outreach event. The experiential opportunity for the virtual participants was adjudication of the PIP grant.

In addition to the working committee members who co-chaired the plenary sessions, 17 participants co-chaired concurrent sessions. For the virtual participants, this entailed liaising with their co-chairs (where possible) and putting together recorded introductions.

Each PIP participant was also paired with a researcher attending the Canadian Institutes of Health Research (CIHR) Institute of Cancer Research Early Career Researcher (ECR) Program, who had volunteered to be part of the PIP. PIP participants and ECRs were matched on common interests, where possible. A one-to-one ratio was not possible because of fewer ECR volunteers than PIP participants, so several ECR volunteers agreed to support more than one participant.

The role of the partnership is two-fold:

- To enable patient partners to better understand the science presented at the CCRC. Science partners are expected to help interpret the information/concepts and address patient partner questions. Science partners may share their own research investigations and explain some of

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[2] These videos are now available on the CCRA website at https://www.ccra-acrc.ca/about-us/patient-involvement/.

[3] This video is available at https://youtu.be/0zRUTdasZbo.

the challenges in conducting research as this will deepen patient partners' appreciation for the research enterprise.
- To provide science partners with a direct and personal experience with a patient partner so that they can better appreciate how cancer research can be enhanced through patient engagement, and, vitally, how clear science communication is an important and integral part of a scientist's toolkit.

Upon conclusion of the program, all new PIP participants were invited to the existing PIP MS Teams, which is a virtual teams environment created after the 2019 PIP. This forum encourages networking and information sharing and "PIP Tuesday," a weekly content scan provided by the CCRA Program Manager, helps facilitate dialogue among members.

In-person Component

Date	Format	Activity
Jun 10	Online	Online Meet & Greet
Jun 13	Online	Online Meet & Greet
Jul 10	Online	Community Outreach Event Planning
Sep 12	Email	Input on Community Outreach Event Promotion/Branding
Oct 13	Online	Community Outreach Event Planning
Oct 30	Email	Connecting to science partners
Nov 10	In-person	Early Career Researcher Program - Dinner event
Nov 11	In-person	Community Outreach Event
Nov 12-14	In-person	Conference (9 participants were concurrent session co-chairs)
Nov 14	In-person	Group Debrief
Dec 5	Online	Invitation to join the PIP MS Team

Virtual Component

Date	Format	Activity
Jun 29	Online	Meet & Greet
Jul 14	Online	Meet & Greet
Aug 9	Online	Preparing for PIP Grant Adjudication webinar
Aug 11	Online	Preparing for PIP Grant Adjudication webinar
Aug 11-Aug 25	Email and/or online	PIP Grant Adjudication and submission of ratings (with partners)
Sep 22	Online	Presentations from top-rated candidates
Oct 13	Email	Decision-making for grant recipient
Oct 30	Email	Connecting to science partners
Nov 12-14	Pheedloop Platform	Conference (8 participants recorded introductions as co-chairs of concurrent sessions)
Dec 1	Online	Group Debrief
Dec 2	Online	Group Debrief
Dec 5	Online	Invitation to join the PIP MS Team

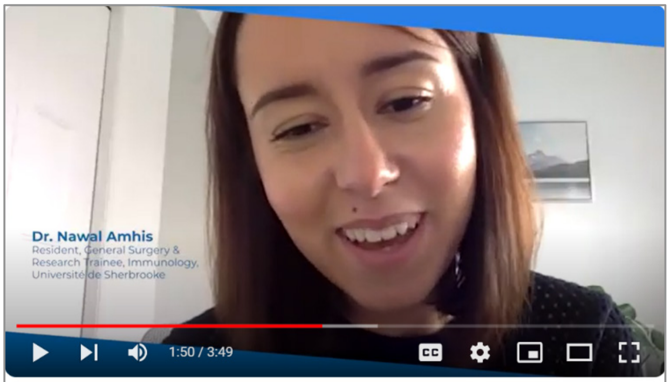
PIP Grant

The 2023 opportunity was re-tooled based on the feedback received from applicants of the 2021 PIP Grant. The changes included: restricting the opportunity to post-doctoral/post-degree fellows; strengthening the application in terms of the requirements for identifying the patient engagement component; changing the application format; and lengthening application submission timelines. The value, $15,000, remained constant as did the grant length (i.e., a one-year duration from Dec 1, 2023 to Nov 30, 2024).

The opportunity was launched on the CCRA website on April 3, 2023 and promoted through CCRA social media, CCRA member organizations, and the CCRC distribution list. Queries were received from seven people, but the informational webinar held on April 17 had only one attendee. The application deadline was July 17, 2023 and four applications were received.

Virtual PIP participants were paired up (10 pairs and one group of 3). They evaluated all four of the applications in a blinded review (i.e., identifiers were stripped from the applications). Applicants were rated on four dimensions (readability of proposal, proposed impact of the research, patient engagement approach, and feasibility of work plan) using 5-point Likert scales. Two of the proposals tied for the highest ratings and those applicants proceeded to the Phase 2 process. Phase 2 involved a 30-minute online meeting with the PIP participants, where applicants could pitch their proposals and respond to questions and feedback from participants. These online meetings were held on September 22. PIP participants submitted their second round of evaluations (done individually) afterwards. Applicants were asked to submit a written statement after the online meetings to address the questions that had been identified by participants, and reviews/ratings of their submission constituted the third round of ratings. Again, both applicants had similar ratings, with one edging out the other by a small margin. The participants voted to declare the highest rated applicant as the grant winner and were supportive of offering the second applicant a free registration to the CCRC.

The grant winner, Dr. Nawal Amhis, is a medical resident in general surgery who is completing a master's degree in immunology with Dr. Lee-Hwa Tai at the Université de Sherbrooke. For her project, "Remodeling of the pancreatic tumour microenvironment with oncolytic virotherapy," she will collect patient tumour samples and develop a pancreatic organoid model to test an oncolytic virotherapy. A patient partner, has been an essential part of this project since its inception, helping to advise on consent forms used to obtain patient samples. This patient partner will also play an important role in knowledge translation. Dr. Amhis will report her findings to the PIP participants and CCRA members in one year's time.



2023 PIP Grant Winner

Community Event

Community outreach has been part of the CCRC since its inception and has been delivered in various ways. For the 2023 program, the community event was determined to be a good opportunity to promote local resources, highlight local research, and provide an opportunity for PIP participants to share their lived experience with the attending public. In addition to display materials from the CCRA, there were 11 exhibitors: Atlantic PATH, Beatrice Hunter Cancer Research Institute (BHCRI), Canadian Breast Cancer Network, Canadian Cancer Society, CIHR Institute of Cancer Research, Craig's Cause Pancreatic Cancer Society, Let's Talk Science (Dalhousie University chapter), Leukemia & Lymphoma Society of Canada, Nova Scotia Cancer Care Program, Young Adult Cancer Canada (YACC), and The Terry Fox Research Institute.


CCRC 2023
THE CANADIAN CANCER RESEARCH CONFERENCE | LA CONFÉRENCE CANADIENNE SUR LA RECHERCHE SUR LE CANCER
PRESENTED BY CCRA ACRC

A community event and panel discussion presented by the Canadian Cancer Research Alliance

Saturday, November 11, 2023
Halifax Convention Centre
1:30 - 4:30 PM

CANCER: Prevention, Treatment & You

A one-hour panel discussion was organized as part of this event. It was moderated by Ms. Eilish Bonang, Anchor, Global News Morning (Halifax), and featured three local researchers:

- Dr. Nathalie Saint-Jacques, MSc, PhD, Senior Epidemiologist, NSH Cancer Care Program, Adjunct Professor, Dalhousie University, Associate Research Scholar, Healthy Populations Institute, and Associate Scientist, BHCRI
- Dr. Michael N. Ha, MD, PhD, FRCPC, Radiation Oncology, Nova Scotia Health, Assistant Professor, Dalhousie University, I3V Clinician Scientist, and Associate Member, BHCRI
- Mr. Tom Christensen, MSc, Clinical Exercise Physiologist (CSEP-CEP) and Research Coordinator, Physical Activity and Cancer (PAC) Lab, Dalhousie University

Eilish also helped promote the event by hosting panelists during her morning show on November 9. Trainees from Dalhousie University, as organized by Carla Ross, Executive Director at BHCRI, helped to distribute posters in the community to advertise the event. Bookmarks were created and distributed through the Halifax public libraries. Two area Sobey's stores donated granola bars and juice for this event.


Community event exhibitor, Charlotte Hall-Coates of The Leukemia & Lymphoma Society with in-person PIP participants (left to right foreground) Wayne Olford, Sheryl Raeburn Olsson, and Pauline McIntyre.

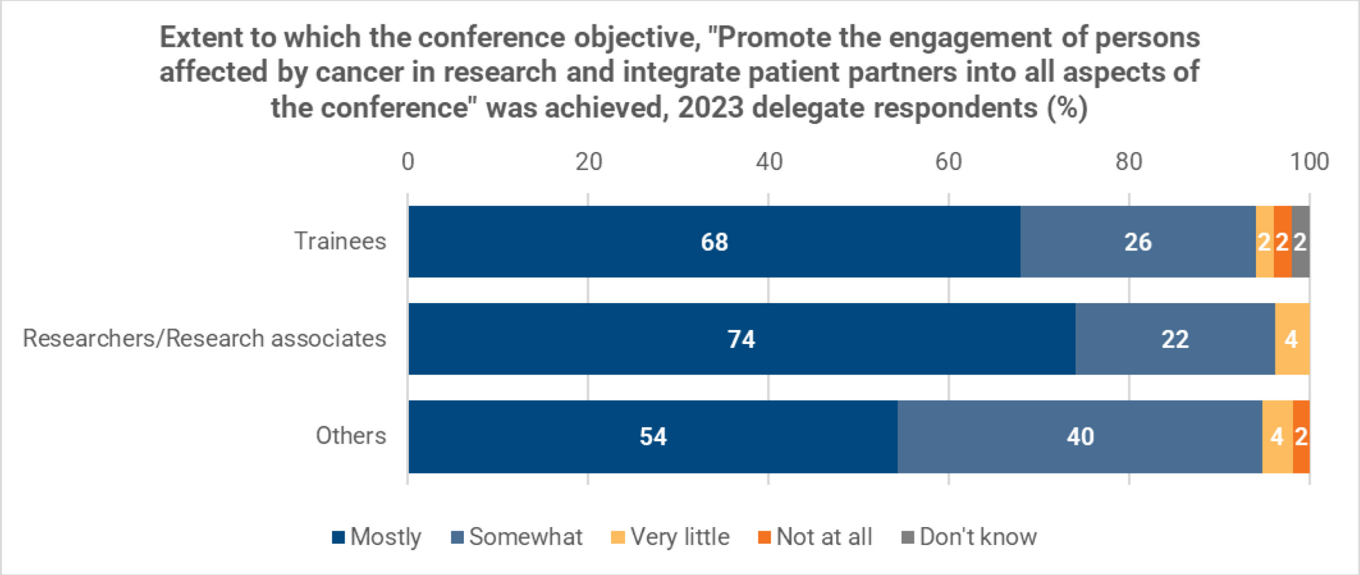
The CCRC, being delayed a week from its usual first weekend of November because of the cancellation of the in-person event in 2021 due to COVID-19, fell on Remembrance Day. Local changes to commemorate the day in Halifax resulted in limited foot traffic in the downtown area and low public participation.

PROGRAM EVALUATION

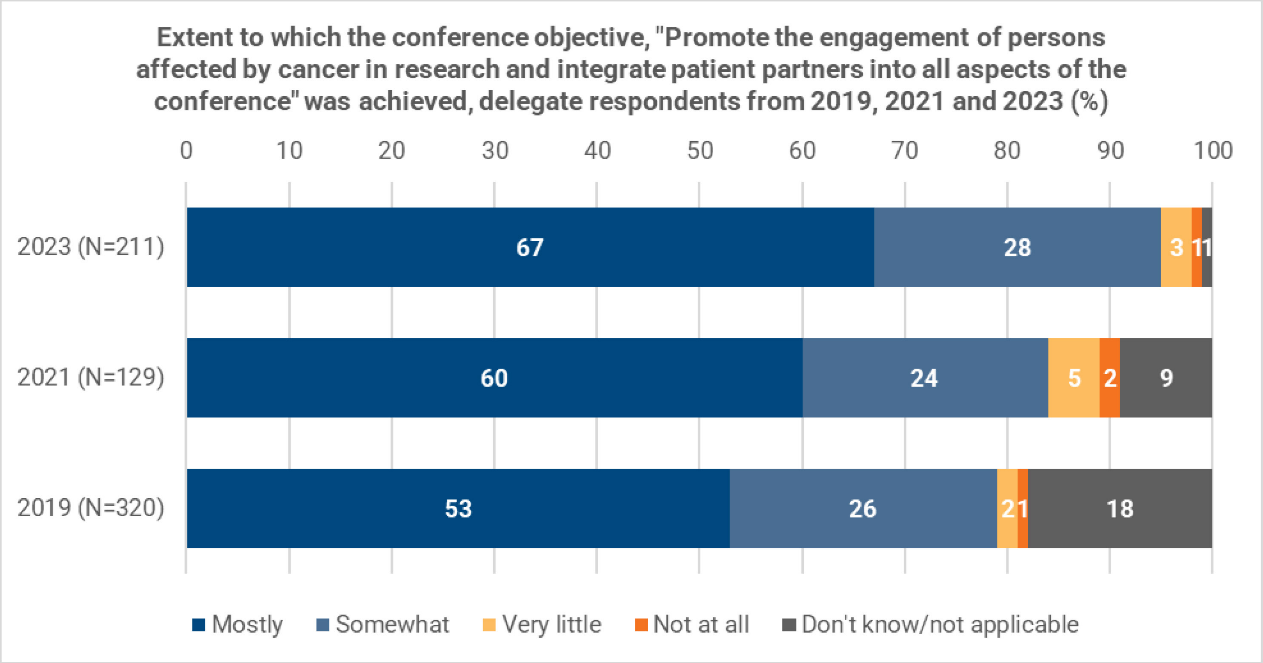
Feedback was collected from several sources: the online post-CCRC delegate (bilingual) survey (QuestionPro); an online post-PIP questionnaire for PIP participants (QuestionPro); a group debrief with in-person PIP participants held immediately after the conference; and two 90-minute group debrief sessions with virtual PIP participants held in December.

POST-CCRC DELEGATE SURVEY

The post-conference delegate survey was completed by 211 attendees (24% response rate). More than half of respondents, regardless of role, felt that the conference objective related to patient involvement was achieved—a higher proportion than the past two programs (graphs below).



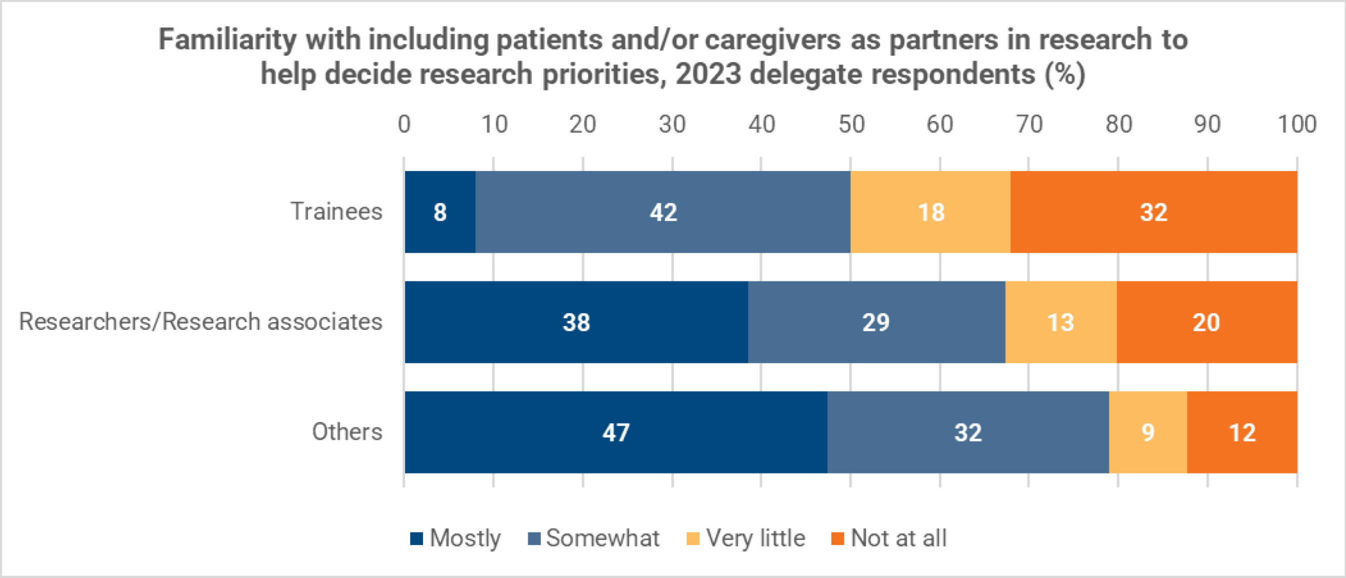
Extent to which the conference objective, "Promote the engagement of persons affected by cancer in research and integrate patient partners into all aspects of the conference" was achieved, 2023 delegate respondents (%)

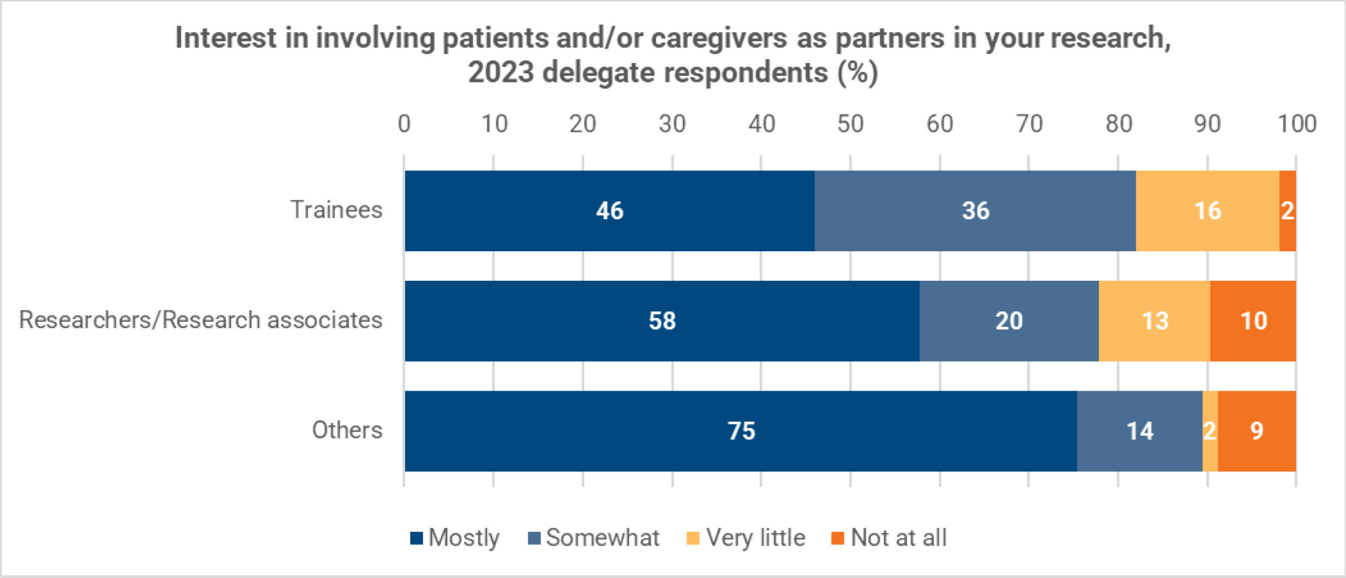


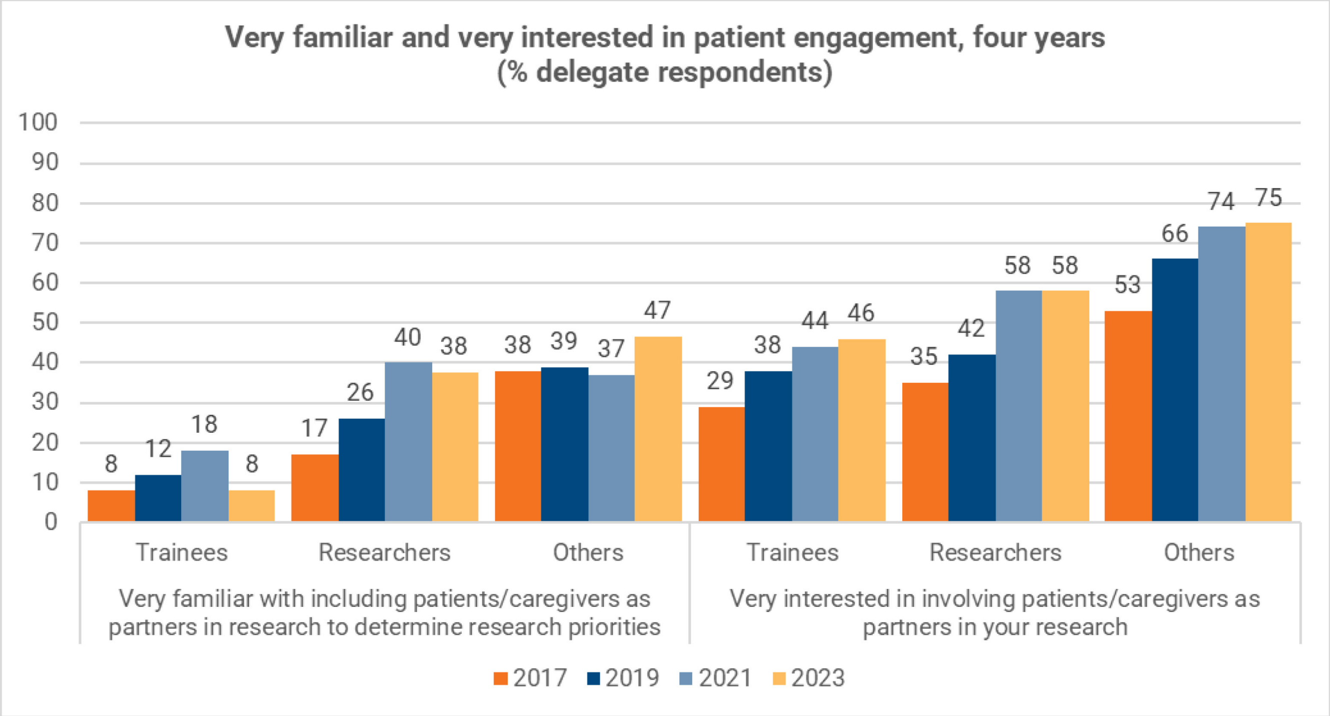
Extent to which the conference objective, "Promote the engagement of persons affected by cancer in research and integrate patient partners into all aspects of the conference" was achieved, delegate respondents from 2019, 2021 and 2023 (%)

Familiarity with including patients and/or caregivers in research to help decide research priorities and interest in involving patients and/or caregivers as research partners was highest among the 'other' group, which included clinicians, patient advisors, and delegates from the charitable sector and industry. There was a lower proportion of trainees that indicated familiarity with patient engagement from previous conferences. (Of note, many of the trainees responding to the 2023 survey had not attended a CCRC in the past and identified as Pillar I researchers.)

A total of 115/211 (55%) of survey respondents indicated that they had networked with a patient partner during the CCRC.

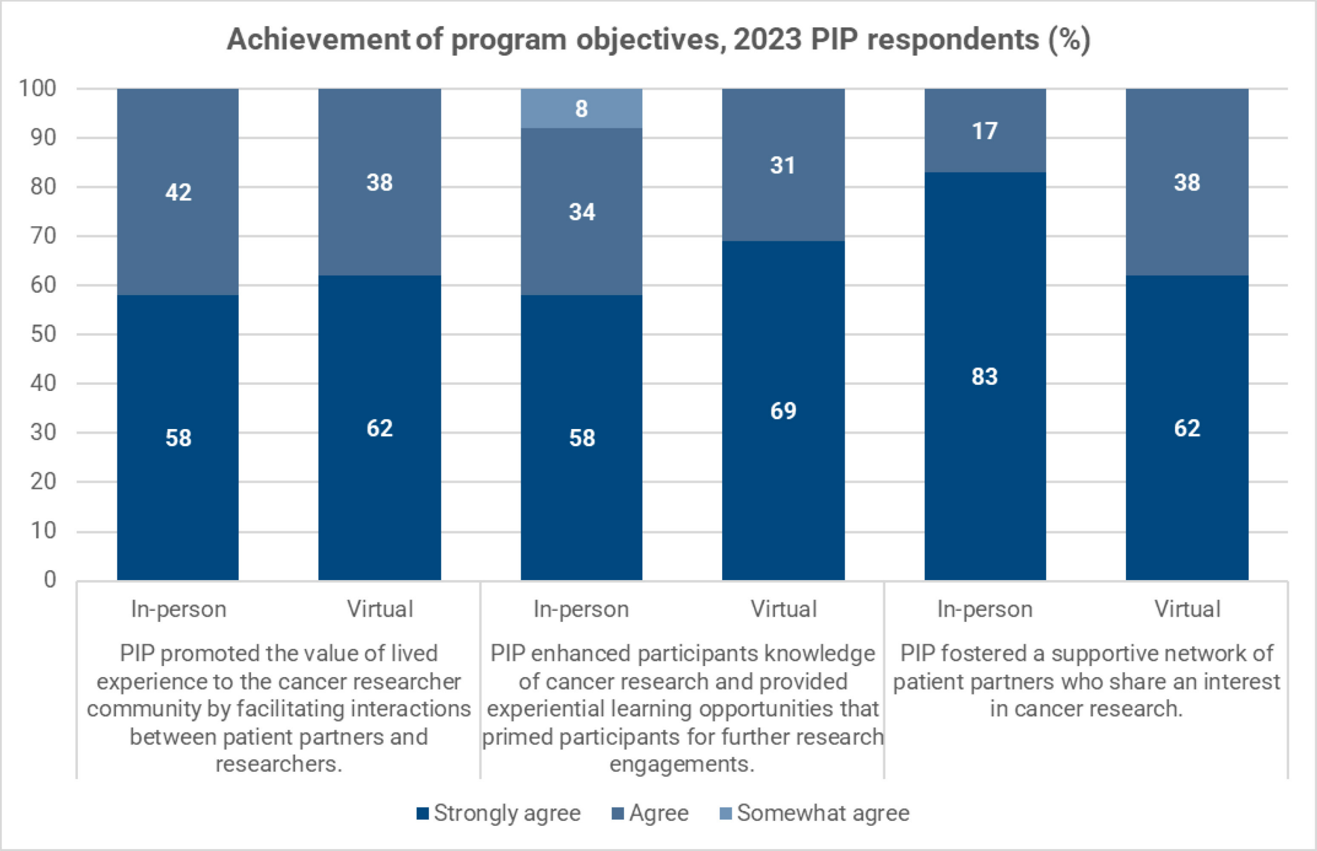

Familiarity with including patients and/or caregivers as partners in research to help decide research priorities, 2023 delegate respondents (%)


Interest in involving patients and/or caregivers as partners in your research, 2023 delegate respondents (%)

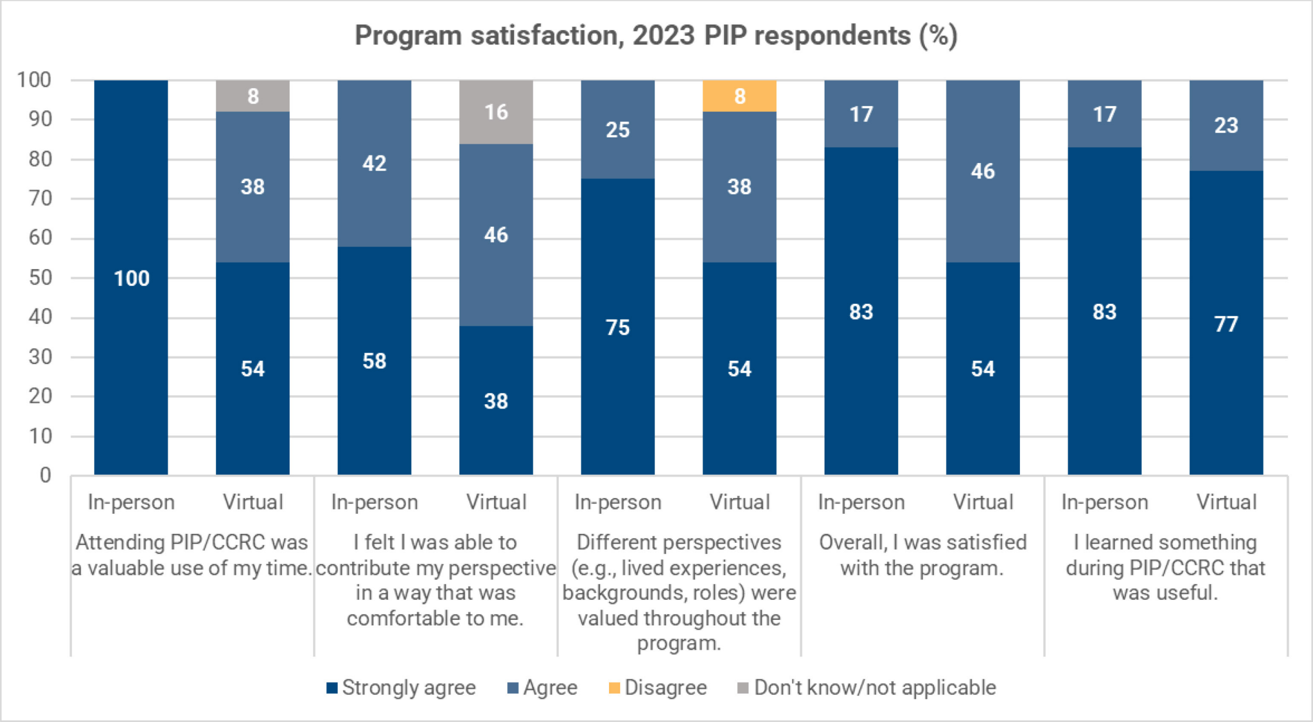


POST-PIP PARTICIPANT QUESTIONNAIRE

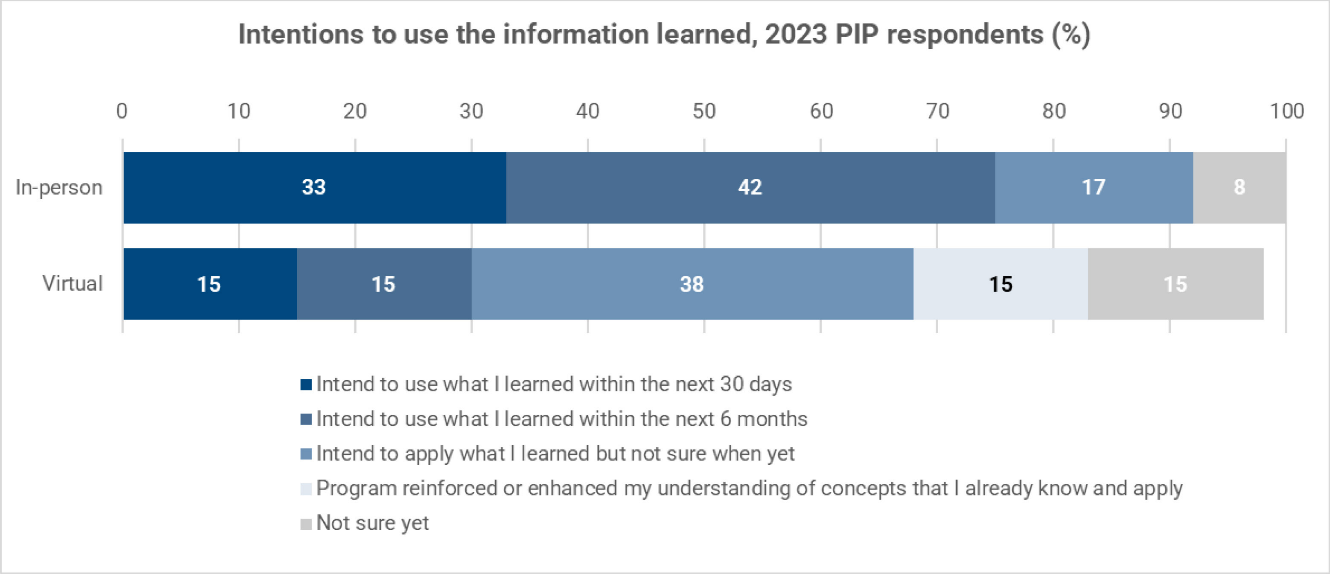
Twenty-five of the 36 PIP participants completed a post-program survey. Response rates were 92% for the in-person participants (12/13) and 57% (13/23) for the participants of the virtual component. Although there was high agreement that the objectives of the program had been met, virtual participants were less likely to agree that the program was a valuable use of their time and that they learned something useful. Connecting with others was limited in the virtual component. In addition, those who participated as virtual co-chairs reported their experience less positively. In both the virtual and in-person components, there was a high proportion of participants who had no or limited contact with their science partners. Although introduced via email by the coordinator, many science partners made no effort to connect with their patient partners.

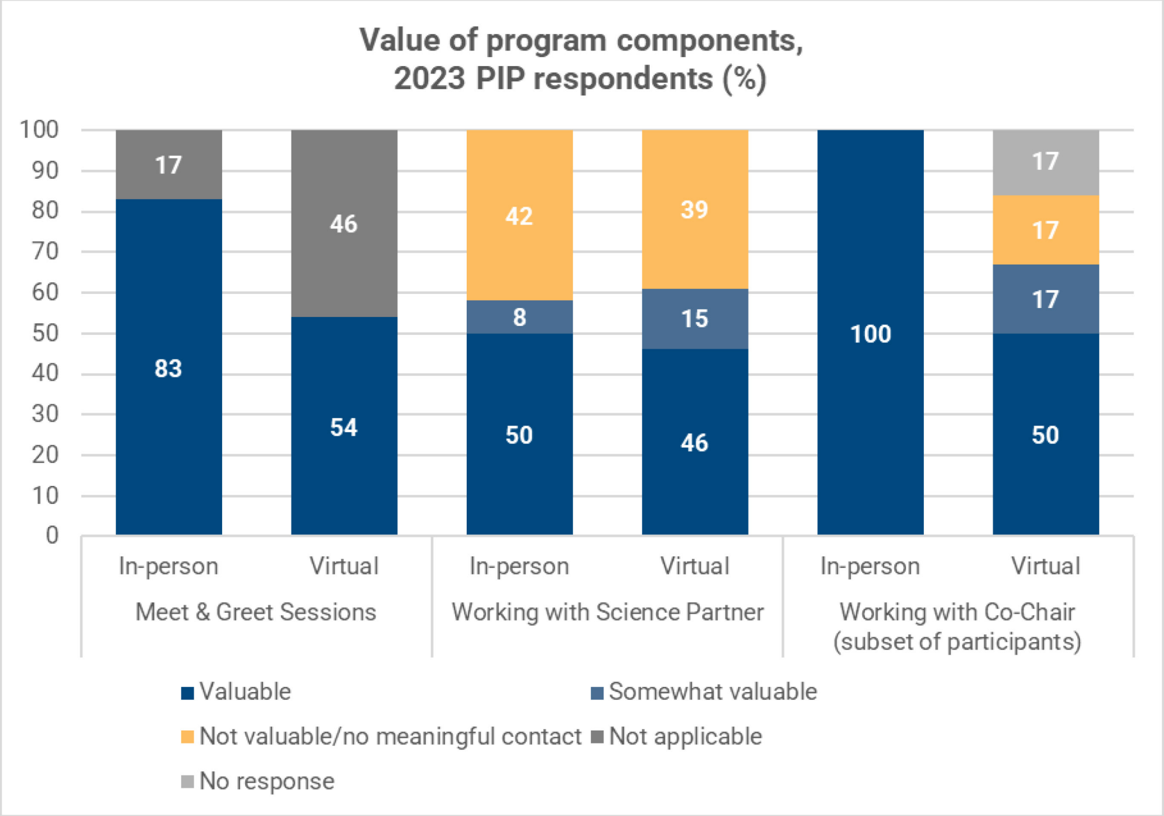


Achievement of program objectives, 2023 PIP respondents (%)



Program satisfaction, 2023 PIP respondents (%)


Intentions to use the information learned, 2023 PIP respondents (%)
0
10
20
30
40
50
60
70
80
90
100
In-person
33
42
17
8
Virtual
15
15
38
15
15
Intend to use what I learned within the next 30 days
Intend to use what I learned within the next 6 months
Intend to apply what I learned but not sure when yet
Program reinforced or enhanced my understanding of concepts that I already know and apply
Not sure yet


Value of program components, 2023 PIP respondents (%)
100
90
80
70
60
50
40
30
20
10
0
17
83
46
54
42
8
50
39
15
46
100
17
17
17
50
In-person
Virtual
Meet & Greet Sessions
In-person
Virtual
Working with Science Partner
In-person
Virtual
Working with Co-Chair (subset of participants)
Valuable
Somewhat valuable
Not valuable/no meaningful contact
Not applicable
No response

IN THEIR OWN WORDS

“It's been a complete honour and privilege to be able to attend an event like this. It was definitely a life-changing experience.” – PIP participant (in person)

“This was a great experience for me. I want to get out and do more/learn more now. Even about my own cancer.” – PIP participant (in person)

“This is the first time I have attended a conference where I observed several patients tell their real-life stories and scientists explain different research directions to save their lives. Medical conferences should be organized in this way to have a true experience of reality.” – Conference delegate

“I learned about the many opportunities for patient engagement. I had no idea these opportunities were out there. I also learned about the value of patient engagement and was very inspired by the researchers who seem to care about it.” – PIP participant (in person)

“My awe in the amount of research and great minds. The commitment to advances in cancer research is strong and almost all research spoke about patient engagement.” – PIP participant (in person)

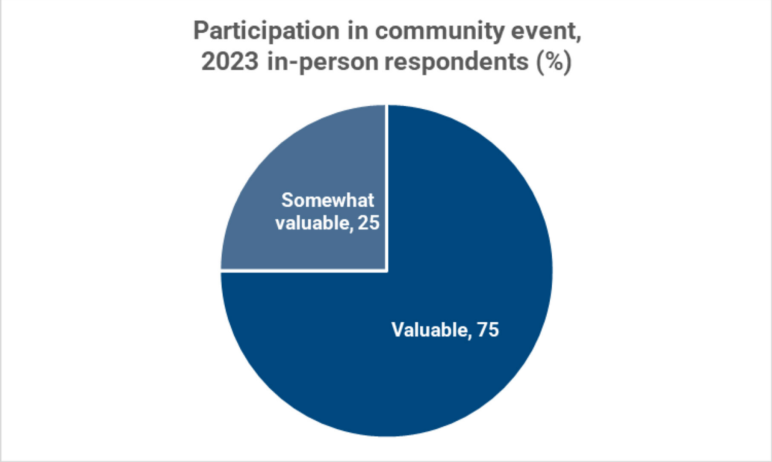
“I really appreciated the role that the patient advisors/patient advocate had in the conference. Sandra Dudych's introduction to the 'Enhancing Palliative, End of Life and Survivorship Experiences' was powerful and brought home the importance of the things that we learned in that session. I consider it one of my key learnings from the conference.” – Conference delegate

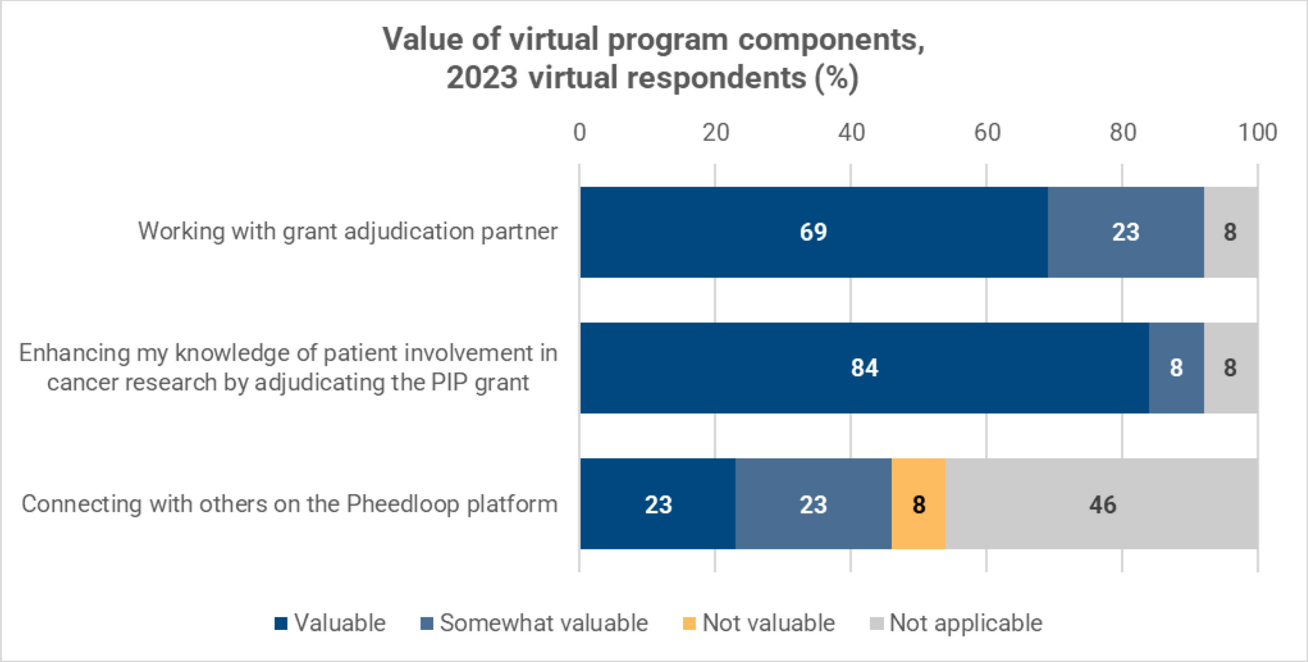
“The support of others going through what you have went through. There have been life-long friendships and connections made.” – PIP participant (in person)

“Becoming a PIP member is a great experience for cancer survivors.” – PIP participant (virtual)

“Research needs to be more patient-oriented and the PIP experience enables patients to become partners in such endeavours.” – PIP participant (virtual)

“Through PIP, my network has grown. I thought that the virtual PIP experience was extremely well-done because we were able to learn a bit about other patient partners. I am especially grateful for the connection made with my adjudication partner.” – PIP participant (virtual)





Dr. Don Desserud, Chair of the 2023 PIP Working Committee, introduces the "Environment and Cancer" plenary, the top-rated plenary according to in-person participants.

Two-thirds of the in-person respondents identified the Environment and Cancer plenary as their top-rated session. In terms of their top concurrent sessions, those most frequently identified were Cancer Research from Atlantic Canada, Workshop – Patient Engagement, Crises Affecting Healthcare, Canadian Partnership for Tomorrow's Health, and Advances in Cancer Immunotherapy. Feedback from virtual participants identified no specific preference/trend.

Dr. Helmut Hollenhorst (at podium) presenting during the "Crises Affecting Healthcare" concurrent with co-chairs (seated) Dr. Robin Urquhart and Ms. Jennifer Coish and speaker, Dr. Craig Earle. This was among the most frequently mentioned "top" concurrent sessions by in-person PIP participants.

DEBRIEF FEEDBACK

Pre-CCRC education

PIP participants suggested providing more information on key definitions, how to interpret graphs, prioritizing your time during the conference, self-care resources, and acronyms.

Science partners

Several participants reported no contact with their science partners, despite this being an opportunity that science partners volunteered to do. This is not to diminish the really excellent science partners, some of whom had been science partners in the past. In-person participants suggested: directly connecting with partners at the ECR networking event; instituting poster walk-abouts with science partners; inviting the science partners to a breakfast or lunch with PIP participants; and formalizing co-attendance at specific sessions so that science partners can help interpret science in real-time.

There were more challenges with linking patient to science partners, particularly given that the 'live' and 'virtual' programs were asynchronous. Suggestions from virtual participants included linking virtual patient partners with virtual researchers and using the virtual platform to connect (e.g., virtual meeting room).

Co-Chairing

While most in-person participants had positive experiences, there is still room for improvement. Increased communication from the conference team has helped, but more is needed. Virtual participants had variable experiences – a couple of participants prepared their recorded introductions without any contact from their co-chairs. The PIP coordinator needs to ensure that contact occurs pre-CCRC. In addition, two co-chairs forgot to play the recorded patient partner introductions during the live event.

Community Outreach Event

Given poor general community engagement, in-person participants felt they required more clarification of their role.

PIP Grant

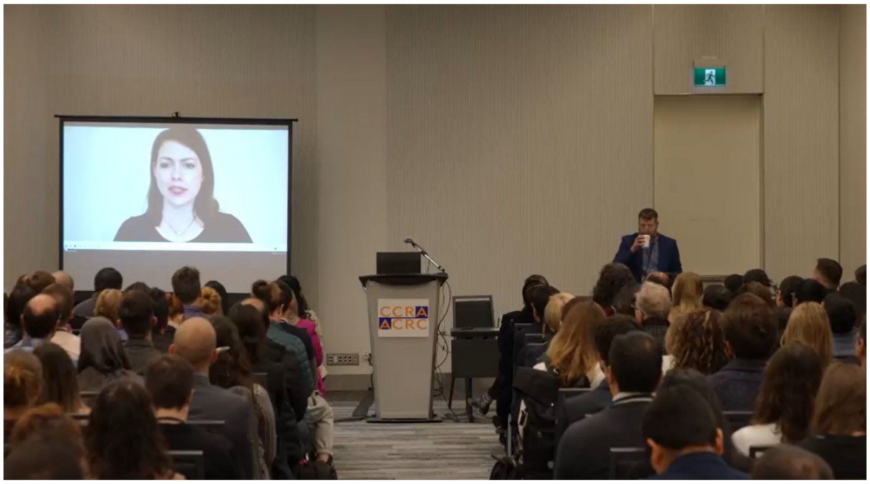
Virtual participants suggested: making it more explicit that the grant is for direct support within the grant guidelines; re-evaluating the grant amount (i.e., $15K may not be enough to attract applicants); enforcing presentation timelines for online sessions with applicants; and ensuring patient engagement is the focus of the presentations given by top-rated applicants.

Posters

No dedicated time was allocated during the poster sessions for presenters to be available at their posters and this reduced opportunities for in-person participants to connect with poster presenters. Suggestions from virtual participants were as follows: ensure that all posters are made available on the platform; improve the search engine (it was very poor with limited search functionality); and provide access to posters in advance of the conference start.

Concurrent Sessions

In-person participants indicated that the room layout could have been improved as the screens were mounted very low and this made it difficult to see the slide presentations. Furthermore, it was suggested that each session be started by asking patients to identify their questions. For some virtual participants, they felt that the recordings were poor for virtual viewing – i.e., the slides/screen couldn't be seen and there were challenges in hearing/understanding speakers. (One participant streamed on her big screen TV as a work-around.) Another commented that the sessions ended abruptly. Other suggestions included: providing more CCRC content on the virtual platform; employing a TED talk format with multiple screens; and providing more content on AYAs/rare cancers.



Virtual participant, Megan Emily Quintal (screen), introduces the "Tumour Microenvironment" concurrent session with co-chair, Dr. Pat Murphy.

Pheedloop Platform

Significant technical issues arose for a couple of virtual participants. Time zone issues for livestreaming were also identified. Deployment of the platform the day before start of the CCRC posed a lot of challenges for participants unfamiliar with virtual platforms. Improving the virtual experience could be enhanced by: providing earlier access to the platform, including an orientation session; creating a 'room' for PIPs on the platform and better opportunities to feel connected; organizing group viewing of one or more sessions and using a guided discussion process; organizing a 'scrum' session to come together with key members of the conference who would do introductions of the sessions for each day as well as an end-of-day review; and offering a lay debrief with specific presenters and a roundtable format offering an opportunity for Q&As.

Other Suggestions

Additional suggestions from in-person participants included: enhancing media attention of the CCRC; providing a printed overview of the conference schedule; incorporating movement breaks and compassion breaks; and ensuring that all working committee members can attend in-person.

PROGRAM COSTS & REVENUE

Support levels were set at $2,500 per virtual participant and $7,000 per in-person participant, with a goal to raise about $80,000 in revenue.

The table below details the support provided. Very importantly, it **does not** include:

- significant in-kind support provided by the CIHR Institute of Cancer Research, who supported the 31 science partners as well as provided dinner for the in-person PIP participants on November 10th
- additional in-kind support provided by the Canadian Partnership Against Cancer for the administration and delivery of the program, financial management (including the PIP grant) and the production of the three-related videos
- the Terry Fox Research Institute's support of airfare for two participants

Organization	$	Type of Support
Alberta Cancer Foundation	7,500.00	Directed (3 participants from Alberta – virtual program)
Brain Tumour Foundation of Canada	2,500.00	Directed (1 participant with brain cancer – virtual program)
Canadian Cancer Society (CCS)	5,000.00	Directed (2 CCS Patient Partners – virtual program)
Canadian Partnership Against Cancer	9,500.00	Directed (2 participants – 1 from in-person program; 1 from virtual program)
Cancer Research Society	2,500.00	Undirected (1 participant – virtual program)
FRQS Oncopole Quebec Cancer Research Network (RRCancer)	2,500.00	Directed (1 participant – virtual program; from Quebec)
Garron Family Cancer Centre/The Hospital for Sick Children	2,500.00	Directed (1 participant – virtual program; from Ontario)
Leukemia & Lymphoma Society of Canada	2,500.00	Directed (1 participant with blood cancer – virtual program)
Ontario Institute for Cancer Research (OICR)	5,000.00	Directed (2 OICR Patient/Family Advisors – virtual program)
The Terry Fox Research Institute (TFRI)	1,699.70	Accommodation and other expenses for TFRI patient partners who were also part of PIP
TOTAL	**41,199.70**	

Projected and actual costs are provided in the table on the following page. Although projected versus actual costs were relatively close, support revenue did not meet the target by nearly $54,000.

Component*	Detail	Projected Costs	Actual Costs	Notes
Virtual	Virtual registrations	2,000.00	1,265.00	
	Virtual platform costs	18,000.00	23,002.30	Pro-rated from actual costs (AV/technical support and costs for Pheedloop platform)
In-person	In-person registrations	6,000.00	4,508.00	
	Catering	7,200.00	7,122.04	
	Airfare/travel	12,000.00	11,958.91	
	Accommodation	16,000.00	14,009.43	
	Ask Me T-shirts	0	407.31	
	PIP room rental	0	2,340.00	
PIP General Admin	Working Committee Compensation	2,500.00	4,600.00	
	Translation	10,000.00	8,027.11	*Actuals, plus estimate for translation of this report
	Certificates (printing, lamination, mailing)	250.00	187.83	
PIP Grant	PIP Grant Amount (no overheads)	15,000.00	15,000.00	Fixed; single grant; one-year term
	Grant winner's travel, accommodation & expenses & CCRC registration, plus runner up reg fee	2,285.00	2,254.00	Runner-up did not attend CCRC
	Other admin as required (legal, translation)	5,000.00	0	Not required for this round
TOTAL		**96,235.00**	**94,681.93**	

**Does not include costs associated with the community event.*

PROPOSED RECOMMENDATIONS FOR 2025 PIP

Increase Support from Wider Range of Support Sources

Without increased support to cover the program costs, the continuation of PIP is in jeopardy. At minimum, a doubling of support in addition to continued in-kind support is needed.

To date, we have relied exclusively on CCRA members and related research organizations to support the program. While industry support may be an opportunity, careful consideration is required to ensure that the program is not perceived as being co-opted by outside interests. Other support models could be used – i.e., instead of using an application process, members could identify patient partners whom they want to attend and pay the related program costs and expenses. Additionally, we could assess interest from private philanthropic organizations. The ability to maintain the branding of PIP as part of the CCRA's CCRC, however, would be an important consideration.

The PIP Working Committee felt that industry support should be explored. They cited the Health eMatters Conference (https://healthematters.ca/our-sponsors/), an initiative of Myeloma Canada that is designed to support skill building for cancer advocates. This event is entirely industry sponsored. Industry-sponsored sessions could be provided prior to/after the main conference program.

Proceed with an In-person Format

A virtual offering addresses accessibility concerns—to quote one of our virtual participants, "Eliminating the virtual component will probably result in eliminating the participation of a few of us (at least me). I don't have the time or resources to travel to Calgary if that is what it will take to participate." However, the costs of offering a hybrid format are significant, and the experience appears to be much less valuable than the in-person one as demonstrated by the participant feedback. Alternative mechanisms to improve the accessibility of research findings to patient partners who require/prefer virtual formats needs to be further developed and could perhaps be offered asynchronous to the CCRC.

It is recommended that consideration be given to an in-person format for 2025 PIP in Calgary. The estimates below are based on scenarios of different number of participants and participants' locations. In this context, "local" refers to participants from Alberta, B.C., and Saskatchewan; "outside" refers to participants from other jurisdictions. Of note, catering (food and beverage) is a major expense and an unavoidable one given that they must be provided by the venue and mealtimes (breakfast and lunch) provide important opportunities for PIP participants to connect and network.

Since PIPs inception, we have not had a program with fewer than 14 participants and we do not recommend a lower number of participants because the integration of patient partners is important to the CCRC writ large and one of the conference objectives.

Estimates - various scenarios	**Registration/ Accommodation /Catering***	**Airfare/ Travel**	**Admin/Room Rental (fixed)**	**Program Total**	**With Grant (+$20K)**
24 participants - 12 local/12 outside	52,200	26,400	18,000	**96,600**	116,600
20 participants - 10 local/10 outside	43,500	22,000	18,000	**83,500**	103,500
16 participants - 8 local/8 outside	34,800	17,600	18,000	**70,400**	90,400
14 participants - 7 local/7 outside	30,450	15,400	18,000	**63,850**	83,850
24 participants - 16 local/8 outside	52,200	24,000	18,000	**94,200**	114,200
20 participants - 15 local/5 outside	43,500	19,000	18,000	**80,500**	100,500

**Based on estimates provided by venue.*

Suspend the PIP Grant for 2025 and a Re-tool if Continued

The experience of adjudicating the PIP grant is a very important one for participants. It does, however, add ~$20,000 to the bottom line, and, within the context of the in-person format, it will require significant additional time commitments from participants. Given that cancer research funding organizations are increasingly engaging patient partners in their grant review processes, the value add of the PIP Grant may not be as great as it was when it was introduced in 2021. As well, the lack of applicants in the 2023 round suggests that more consideration needs to be given to the design of this opportunity. A re-tool of this grant opportunity in tandem with a virtual PIP offering for 2026 will be slated for consideration by the CCRA membership in 2025, and could perhaps be announced at the CCRC 2025.

Continue to Hone the Valued Aspects of the Program

Co-chairing and working with science partners are important elements of participants' experience. It is hoped that the CIHR Institute of Cancer Research will continue to offer the support of participants of its ECR program to fill the science partner component. Ensuring pre-CCRC contact is needed, and more measures can be taken to better support patient partners. Furthermore, approaches to enhance the accessibility of the science presented in the sessions as well as in the posters need to be developed.

2023 PIP SUPPORTERS

CIHR IRSC
Institute of Cancer Research
Institut du cancer

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

Alberta Cancer FOUNDATION

Canadian Cancer Society
Société canadienne du cancer

OICR / IORC
Ontario Institute for Cancer Research
Institut ontarien de recherche sur le cancer

THE TERRY FOX RESEARCH INSTITUTE
L'INSTITUT DE RECHERCHE TERRY FOX

braintumour foundation OF CANADA
LA FONDATION canadienne des tumeurs cérébrales

Société de recherche sur le cancer
Cancer Research Society

SickKids Garron Family Cancer Centre

LEUKEMIA & LYMPHOMA SOCIETY OF CANADA
SOCIÉTÉ DE LEUCÉMIE & LYMPHOME DU CANADA

RRCANCER Réseau de Recherche sur le Cancer
ONCOpole
Pôle cancer du FRQS