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 2025 PIP and Recommendations for Future Programs

2026-Apr-15

CONTENTS

ACKNOWLEDGEMENTS

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In addition to the Working Committee, the participants of the 2025 program included: Randy Baldwin, Jennifer Coish, Howard Dellar, Alyssa Dickey, Sandra Dudych, Kirsten Efremov, Justin Gaudet, Lucy Ioannoni, Suad Ismail, Natalie Kwadrans, Camille Leahy, Cara MacInnis, PhD, Sherry Metcalfe, Katharine Palmer, Darrin Park, Megan Quintal, Megan Sewell, Sundas Shamshad, Eddy Szczerbinski, Valentine Thompson and Robyn Wood.

Twenty-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. All but one were part of the Canadian Institutes of Health Research (CIHR) Institute of Cancer Research (ICR) Early Career Researcher (ECR) Program. They were: Vasudeva Bhat, PhD, Western University, Miffy Hok Yan Cheng, PhD, University of British Columbia, Jawad Chishtie, MBBS, PhD, University of Toronto, Vikas Garg, MD, DM, Windsor Regional Hospital, Zhimeng Jia, MD, Sinai Health, Shuk On Annie Leung, MD, McGill University, Catrina Loucks, PhD, University of British Columbia, Elodie Lugez, PhD, Toronto Metropolitan University, Ronda Lun, MD, MSc, FRCPC, University of Calgary, Arata Matsuyama, DVM, PhD, Ontario Veterinary College of Medicine, University of Guelph, Scott McComb, PhD, National Research Council Canada and University of Ottawa (not part of the ECR program), Éva Michaud, PhD, McGill University, Mathieu Quesnel-Vallières, PhD, Université de Sherbrooke, Sara Shearkhani, PhD, University of Toronto, Fay Strohschein, PhD, University of Calgary, Ying Lisa Tang, PhD, University of British Columbia, Joanne Tay, PhD, University of Windsor, Yiming Wang, MD, PhD, FRCPC, The Hospital for Sick Children, Amanda Wurz, PhD, University of the Fraser Valley, Stephanie Xie, PhD, Princess Margaret Cancer Centre, and Karen Zhang, PhD, C.Psych, McMaster University.

In addition, the following researchers led the plenary and concurrent sessions with PIP participants as co-chairs: Ludmil Alexandrov, PhD, University of California San Diego, Touati Benoukraf, PhD, Memorial University of Newfoundland, Darren R. Brenner, PhD, University of Calgary, M. Dean Chamberlain, PhD, University of Saskatchewan, Jennifer Chan, MD, University of Calgary, Winson Cheung, MD, MPH, FRCPC, University of Calgary, Andrew Craig, PhD, Sinclair Cancer Research Institute, Queen's University, Pierre-Olivier Gaudreau, MD, PhD, MPs, FRCPC, Spencer Gibson, PhD, University of Alberta, Stephanie Grover, MSc, CCRP, PMP, ACCESS, KD King, RN, PhD, Alberta Health Services, MacEwan University and University of Alberta, Alexandra King, MD, FRCPC, FCAHS, Nipissing First Nation, University of Saskatchewan, Angeline Letendre, RN, PhD, Co-Chair, First Nations, Inuit and Métis Working Group, Madeline Li, MD, PhD, Princess Margaret Cancer Centre - University Health Network; University of Toronto, Fei-Fei Liu, MD, FRCPC, FASTRO, FCAHS, CIHR ICR, Princess Margaret Cancer Centre, University of Toronto, Kiven Erique Lukong, PhD, University of Saskatchewan, Rebecca Mercer, PhD, Canadian Centre for Applied Research in Cancer Control (ARCC), Hermann Nabi, PhD, HDR, Centre de recherche du CHU de Québec-Université Laval; Université Laval, Hanne Ostergaard, PhD, University of Alberta, Joel Pearson, PhD, University of Manitoba, Paula Robson, PhD, Alberta Health Services, Christian Steidl, MD, PhD, BC Cancer, Robin Urquhart, PhD, Dalhousie University, Josie Ursini-Siegel, PhD, McGill University and Linda Watson, PhD, Alberta Health Services.

Many staff at the Canadian Partnership Against Cancer supported the program: Harini Aiyer, PhD, Specialist, Scientific Engagements at the Canadian Partnership Against Cancer and Sara Goncalves, Coordinator, First Nations, Inuit and Métis-Led Research worked to ensure that PIP participants were well-profiled at the conference in social media and on the conference app; Kris Atterbury, Specialist, Production and Design, produced the PIP promotional videos; Jessie Yin, Controller, and Sheila Zhang, Senior Accountant, managed the in-flow and out-flow of supporter contributions and program expenses; Neda Didani, Coordinator, First Nations, Inuit and Métis-Led Cancer Strategy, assisted with logistics and shipping; and Amber Crane, Administrative Assistant, assisted with travel arrangements and expense claim reimbursements. A special thank you to Lucille Dupuis, John Corriveau's wife, who assisted with conference registration.

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 contact info@ccra-acrc.ca

Photographs from the CCRC used in this report were taken by Dan MacDonald/Purple House Photography.

SUMMARY

A four-person Working Committee planned the 2025 Patient Involvement in Cancer Research Program (PIP), which was integrated with the 2025 Canadian Cancer Research Conference (CCRC). Twenty-six participants were selected from 92 applicants, and 25 people completed the program. PIP participants had virtual meet and greets, webinars, in-person networking events, and a tailored afternoon of programming prior to the start of the CCRC.

The 2025 PIP was supported by 12 Canadian Cancer Research Alliance (CCRA) members and affiliated organizations, providing both cash and in-kind support.

Twenty-two of the 25 participants completed the PIP post-program evaluation (88% response rate). All indicated that the PIP was worth their time to attend. Most participants felt the program had relevance and rated the various components as valuable.

Participants had several suggestions to improve future programs. Ensuring that participants meet in-person with their science partners prior to the CCRC was identified as very important. In addition, it was recommended that a template or standardized approach be taken to the time allotment and roles for co-chairs of the concurrent sessions. Improving the poster experience was also identified as needed. Given escalating costs for conference delivery post-COVID, however, greater financial support is needed for the program to break even. Capping the number of participants may be required to ensure that the program is economically viable.

A post-conference delegate survey showed that there has been increased familiarity and interest in involving patients in cancer research among conference delegates, two areas that we have assessed since the 2019 CCRC to gauge how awareness of patient engagement among the research community has changed.

17 of the 25 PIP participants of 2025. Photo taken on November 4, 2025 outside the room designated for PIP at the Calgary Telus Convention Centre.

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 via the PIP MS Teams, an online forum co-designed by participants after the 2019 PIP.

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.

Dr. Rosilene Kraft, Chair of the PIP Working Committee, during the opening ceremony of the CCRC.

PROGRAM APPLICANTS AND PARTICIPANTS

The call for participant applications was made on March 3, 2025. The program was promoted on the CCRA website and social media channels, through the existing PIP network, and by individual CCRA member organizations.

KEY ABBREVIATIONS

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

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

The online application (in both official languages) was prepared in QuestionPro. Applications were due on May 8, 2025.

APPLICANTS

A total of 92 applications were received by the deadline, the highest number to date. 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 92 applicants, most selected the pronouns she/her (74%) and 45% were under the age of 50. Applicants resided in nine provinces. Sixty-five percent had cancer, 18% were caregivers, and the remaining 17% were both. Among those who had/have cancer, 84% received their initial cancer diagnosis five or more years ago. Breast and blood cancers were the most frequent cancer types. Among all applicants, 41% reported having been directly involved in cancer research.

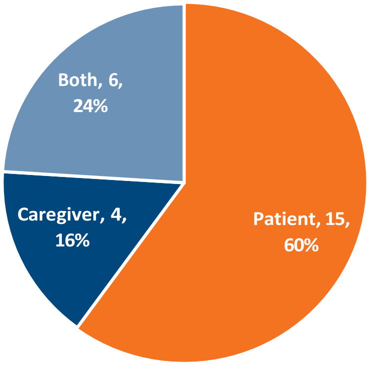
PARTICIPANTS

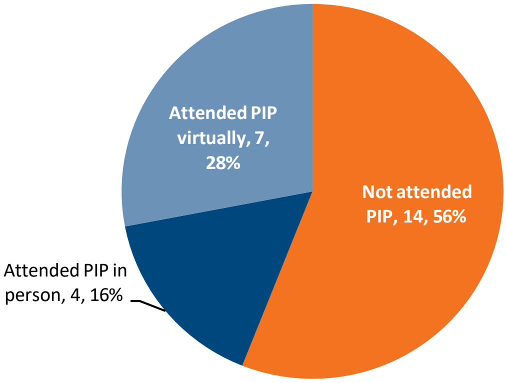
Participant selection is a balancing act, designed to optimize the diversity of program participants as well as the needs of organizations supporting the program. Applicant selection was based on numerous factors – geography, gender, age, cancer experience, and research experience (a mix of inexperienced and experienced research advocates is preferred). Twenty-two applicants (in addition to the Working Committee) were selected. One participant had to opt out in the weeks ahead of the conference for personal reasons.

A demographic summary of all 25 participants of the 2025 PIP is presented below. Eleven participants had previously attended PIP, four in person and seven as part of the 2023 virtual program.

PIP participants listening to speakers during one of the plenary presentations.

Age Group	She/Her	He/Him	N
35 to 49 years	11	1	12
50 to 69 years	7	4	11
70 or older	0	2	2
TOTAL	**18**	**7**	**25**

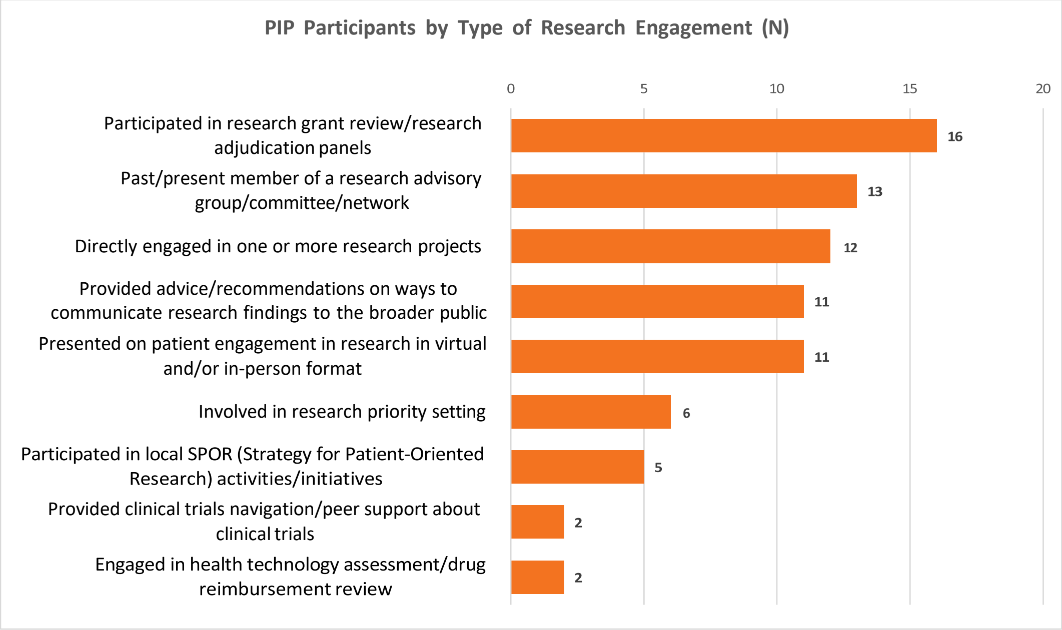

PIP Participants by Perspective (%)


PIP Participants by Previous PIP Involvement (%)

	Community Size				
Province	**Rural**	**Small**	**Medium**	**Large**	**N**
Alberta		1	1	5	7
British Columbia				1	1
Manitoba		1		2	3
Newfoundland & Labrador	1	1			2
Nova Scotia				1	1
Ontario		1	2	3	6
P.E.I.		1			1
Quebec				3	3
Saskatchewan				1	1
TOTAL	**1**	**6**	**4**	**15**	**25**

	Years Since Initial Diagnosis			
Initial Cancer Diagnosis	**Less than 5 years**	**5-10 years**	**More than 10 years**	**N**
Appendix		1		**1**
Blood		2	4	**6**
Bone			1	**1**
Brain			1	**1**
Breast	1	7	1	**9**
Colorectal		1	1	**2**
Melanoma		1		**1**
Pancreatic		1		**1**
Prostate		1	1	**2**
Multiple			1	**1**
TOTAL	**1**	**14**	**10**	**25**

Self-rated experience	**N**
No involvement	5
Participant in a research study and/or clinical trial	8
Directly engaged in cancer research	12
TOTAL	**25**


PIP Participants by Type of Research Engagement (N)

PIP COMPONENTS

Working Committee

As has been done since 2021, this year's program was directed by a working committee comprised of four patient representatives, all of whom had previously attended PIP. Dr. Rosilene Kraft, patient representative on the CCRA Advisory Board since January 2024 and participant of the 2021 and 2023 programs, was the chair. Other patient/family representatives on the CCRA Advisory Board, Adrienne Co-Dyre and Chantale Thurston, were also members. John Corriveau, a participant of the virtual cohort in 2023 and local to Calgary, was the fourth member.

Rosilene and Chantale were cross appointed to the CCRC Executive Planning Committee (EPC), the group that oversees the development of support opportunities and the logistical aspects of the conference. Adrienne and John served on the CCRC Scientific Program Committee (SPC). The SPC spearheaded the development of scientific content by identifying novel session themes, chairs, and speakers, and oversaw abstract review and selection.

The working committee provided invaluable direction, support, and feedback in terms of the program format, process and materials. In addition, members helped to create two videos on PIP, which were aired during the CCRC, helping to inform conference delegates about the program and elevate the patient profile.[2]

In terms of the CCRC itself, all four members were co-chairs for the four plenary sessions at the CCRC, with Rosilene also doing double-duty as a concurrent co-chair.

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

PIP video featuring Adrienne Co-Dyre shown in the plenary hall.

Program Components

Twenty-three of the 24 concurrent sessions were co-chaired by PIP participants. Each PIP participant was also paired with a researcher attending the Canadian Institutes of Health Research (CIHR) Institute of Cancer Research (ICR) 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 information about their own research and explain some of 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 person with lived or living experience with cancer. This experience helps science partners better appreciate patient priorities, how cancer research can be enhanced through patient engagement, and 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. "PIP Tuesday," a weekly content scan provided by the CCRA Program Manager, helps facilitate dialogue among members and alerts members to research and educational opportunities.

Key dates for the 2025 program are provided below.

Date	Format	Activity
May-June	Calls	Individual calls with selected applicants
July 21	Online	Meet & Greet
July 22	Online survey	Poll of topics for pre-webinars
Aug 11	Online	Meet & Greet
Aug 18	Online	Meet & Greet
Sept 29	Pre-webinar	"Cancer Biology 101 for PIP" delivered by Dr. Joel Pearson (University of Manitoba)
Oct 20	Pre-webinar	"The Biology Basics for Immunotherapy" delivered by Dr. Scott McComb (National Research Council of Canada)
Sept-Oct	Email/online	Connecting to session co-chairs and to science partners
Oct 31	In-person	Meet & Greet
Oct 31	In-person	Early Career Researcher Program – Networking dinner event
Nov 1	In-person	Tour of the Arthur J.E. Child Comprehensive Cancer Centre
Nov 1	In-person	PIP Program
Nov 2-4	In-person	Conference
Nov 4	In-person	Group Debrief
Nov 10	Online	Invitation to join the PIP MS Team

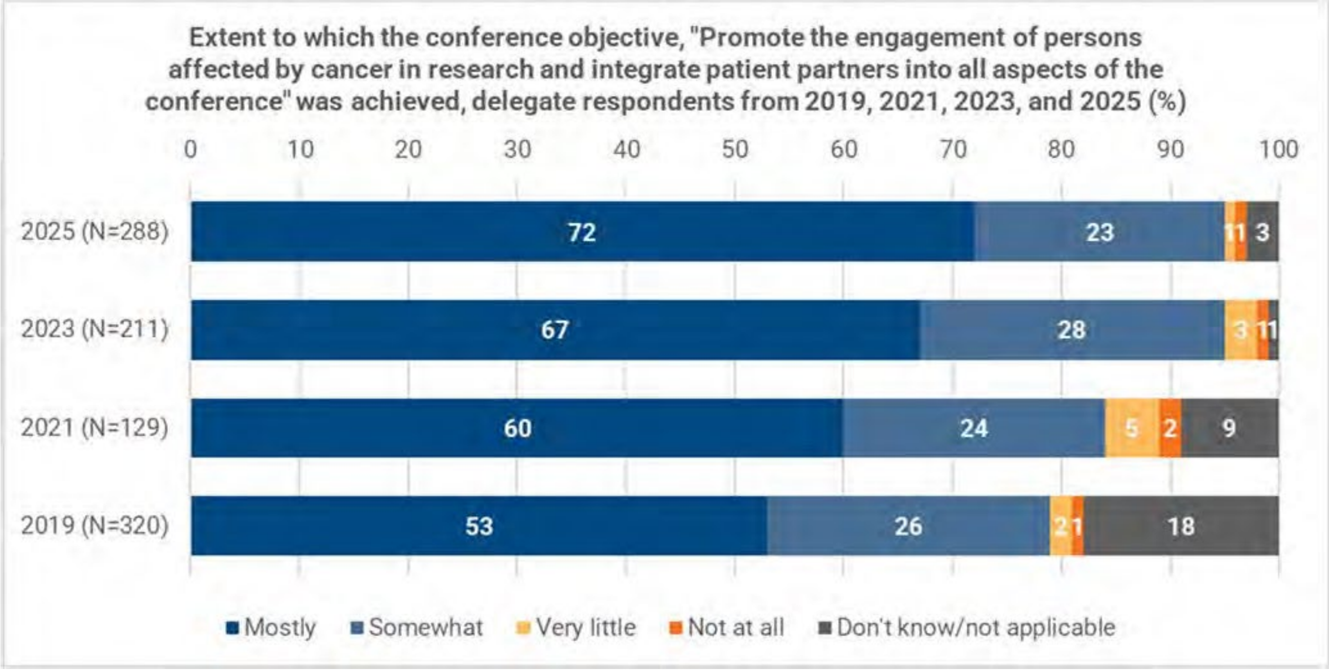
PROGRAM EVALUATION

Feedback was collected from several sources: the online post-CCRC delegate (bilingual) survey (QuestionPro), an online post-PIP questionnaire for PIP participants (QuestionPro), and an in-person group debrief held immediately after the conference's conclusion on November 4.

POST-CCRC DELEGATE SURVEY

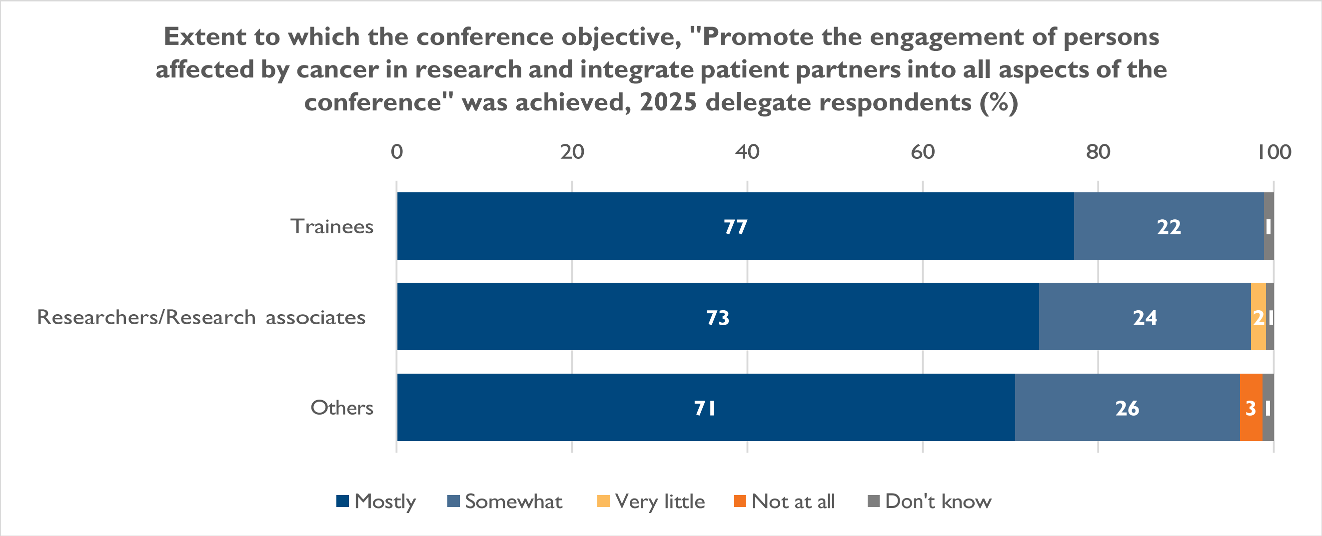
The delegate survey has used the same questions on patient engagement since the 2019 CCRC and is reported here to gauge how awareness of patient engagement among the research community has changed over time. The value of PIP is not only to build capacity among the participants, but to help foster awareness among the trainees and researchers attending the conference.

The post-conference delegate survey was completed by 288 attendees (27% response rate). More than 70% of respondents, regardless of role, felt that the conference objective related to patient involvement was achieved—a higher proportion than the past three programs (graphs below).

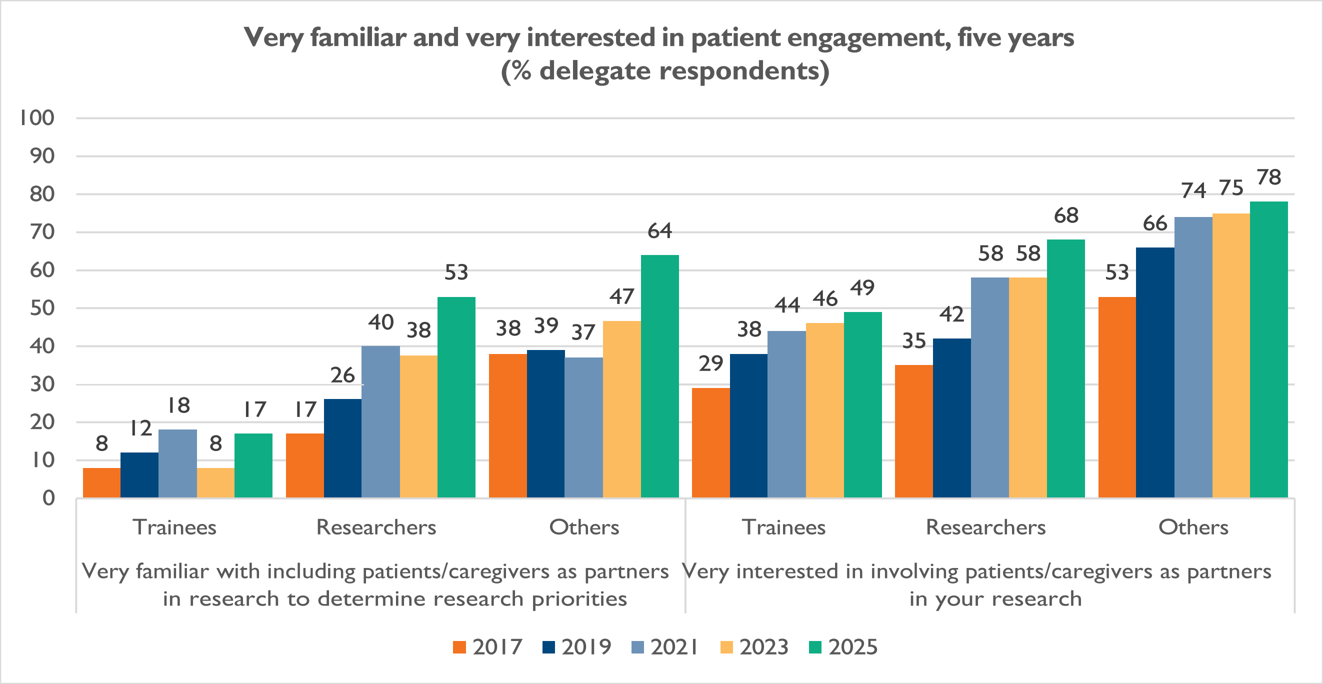


Extent to which the conference objective, "Promote the engagement of persons affected by cancer in research and integrate patient partners into all aspects of the conference" was achieved, delegate respondents from 2019, 2021, 2023, and 2025 (%)

> "…it was way beyond what I had expected. This came from the conference and all the information I learned and gathered - but most of all this hope and inspiration came from all the genuine and heartfelt contacts I had with leaders, players, researchers and patients that I met. I also felt a lot of interest and genuine will to learn from each other from the participants. I felt like I was in the right place with the right people."
>
> – PIP participant



The proportion of post-delegate respondents from 2025 (green bars) who reported being very familiar and very interested in engaging patients and/or caregivers in research was similar (Trainees)[3] or higher (Researchers and Others) than the proportions reported in previous conferences (graph below).



As with previous post-delegate survey results, the ‘other’ group, which included clinicians, patient advisors, and delegates from the charitable sector and industry, was most likely to indicate familiarity with and interest in engaging patients and caregivers as partners in research (graphs below).

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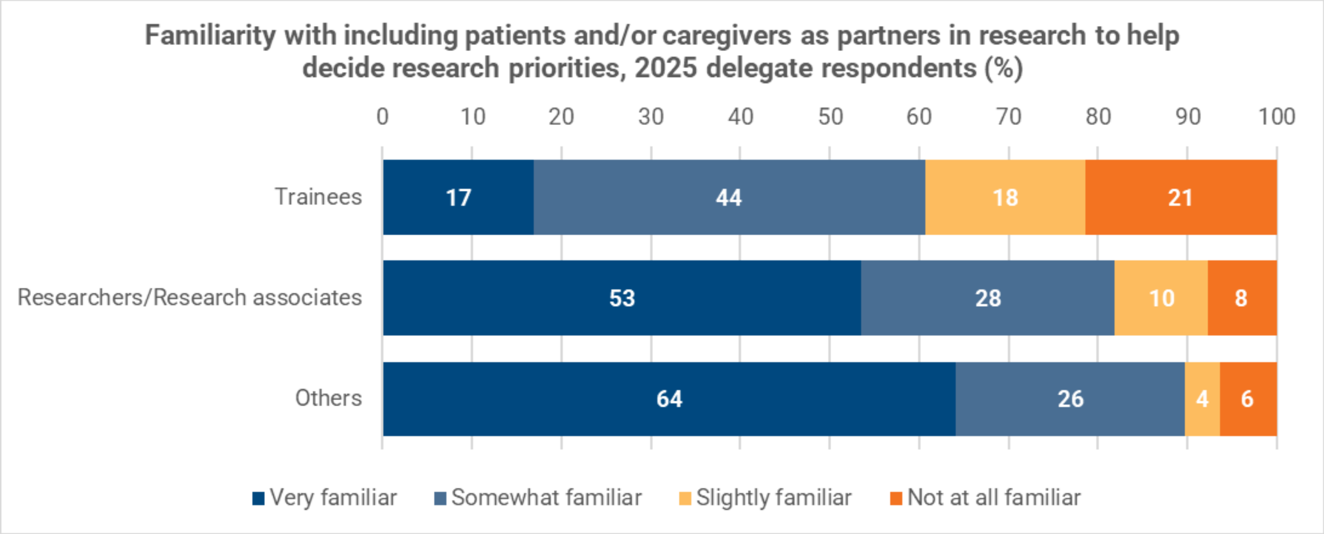
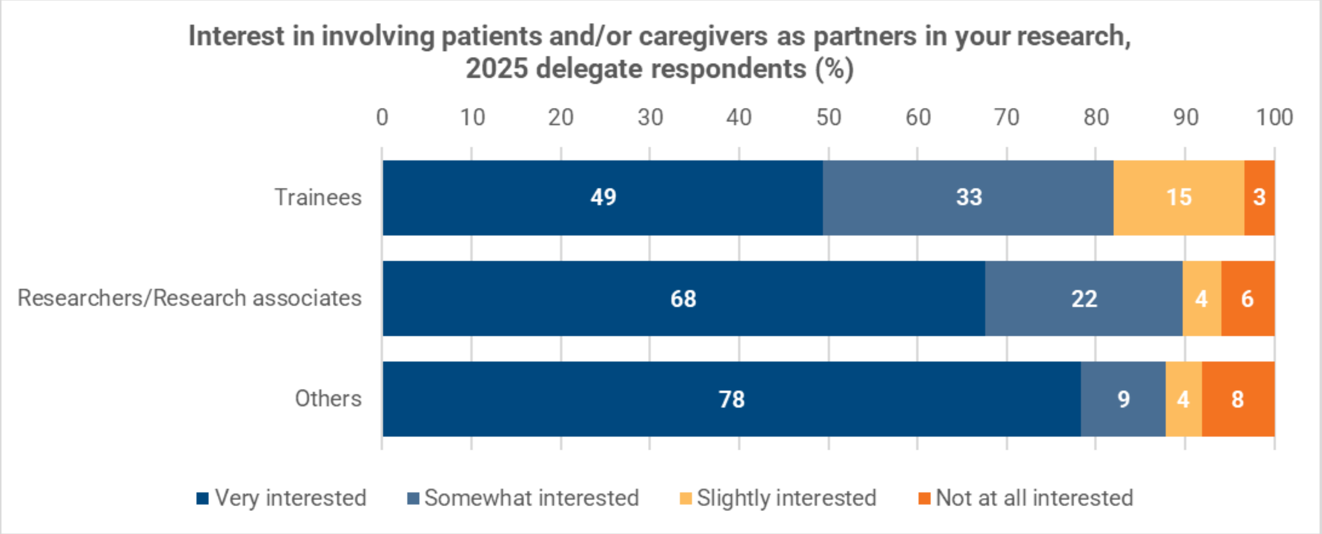
[3] Trainees are students pursuing undergraduate or graduate degrees or completing postdoctoral work.

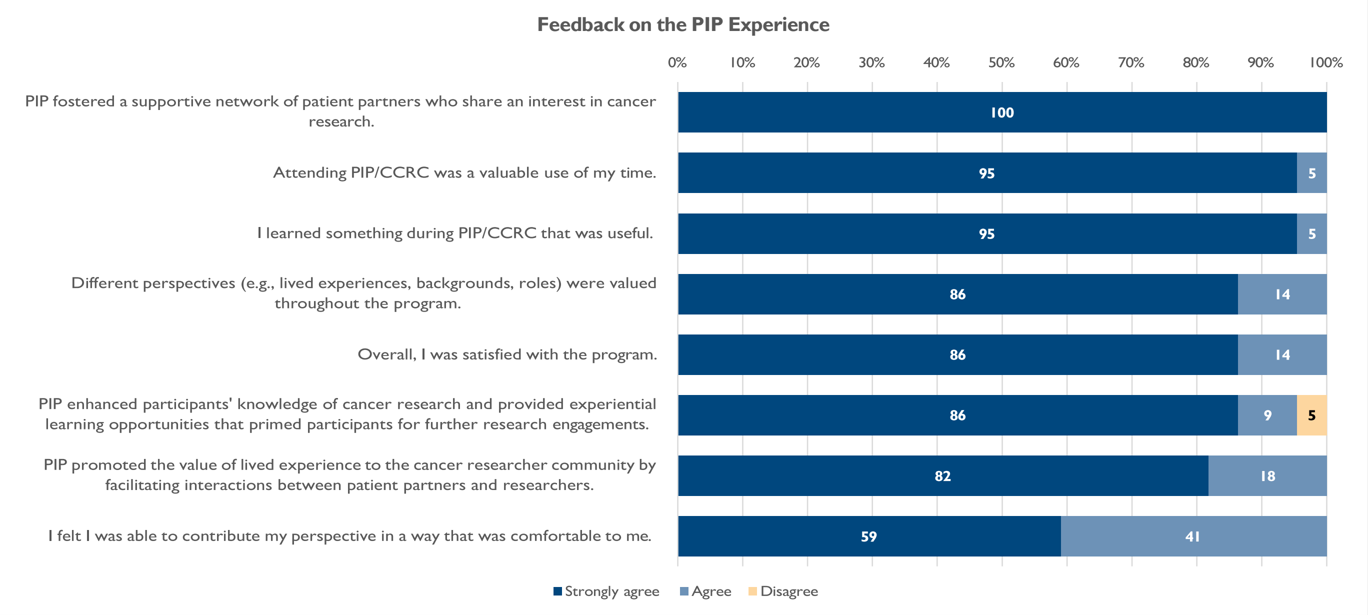




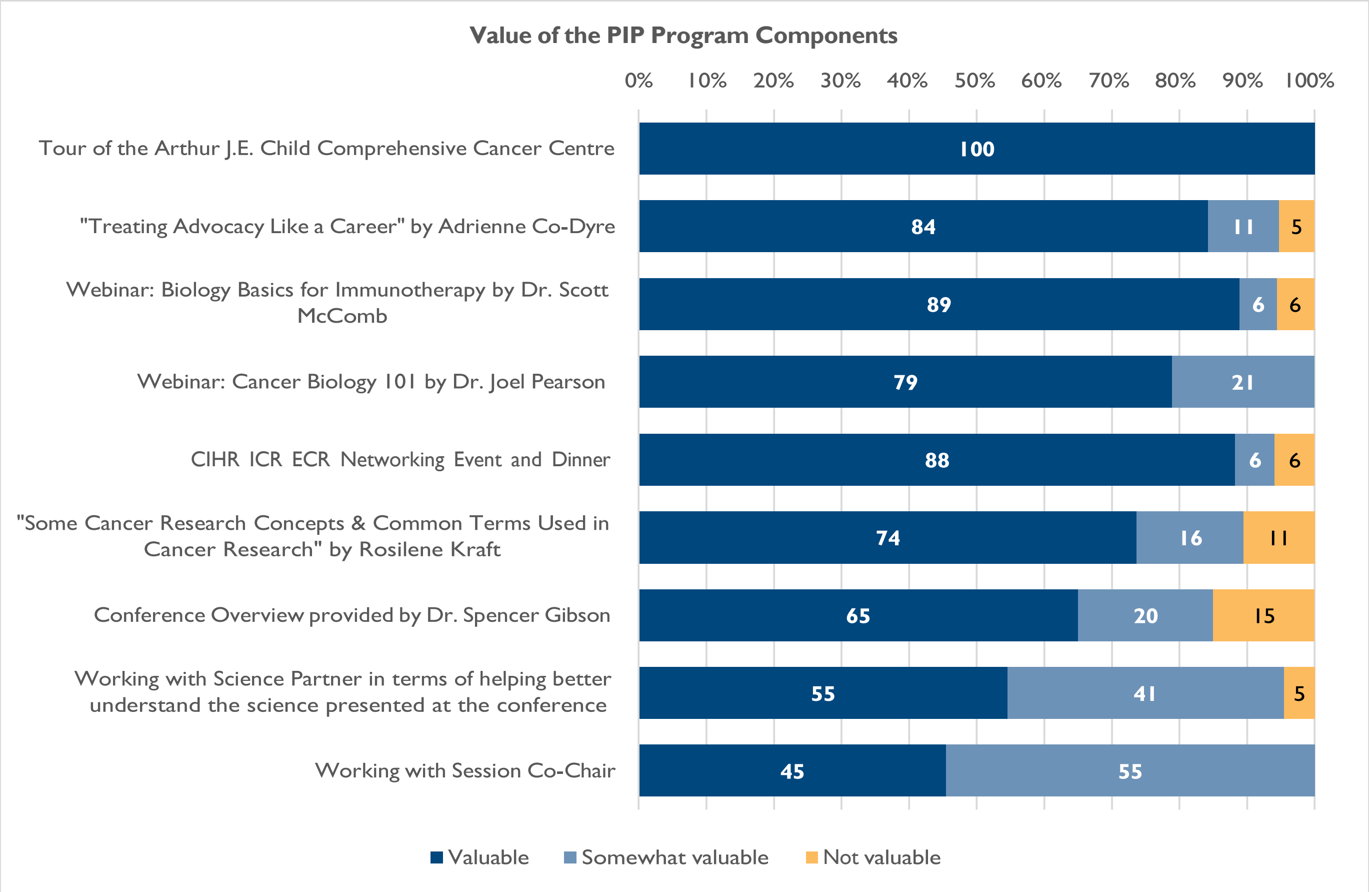
Forty-five percent of trainees responding to the post-event survey indicated that they spoke with a patient advocate while at the conference; this was 60% for researchers/research associates.

POST-PIP PARTICIPANT QUESTIONNAIRE

Twenty-two of the 25 PIP participants completed a post-program survey. All respondents felt that PIP was worth their time to attend. There was strong agreement on most objectives related to the program although less so with the statement "I felt I was able to contribute my perspective in a way that was comfortable to me" (graph below).



Specific components of the program were perceived to be of varying levels of value. All respondents participating in the tour of the cancer centre felt the experience was valuable (graph below).

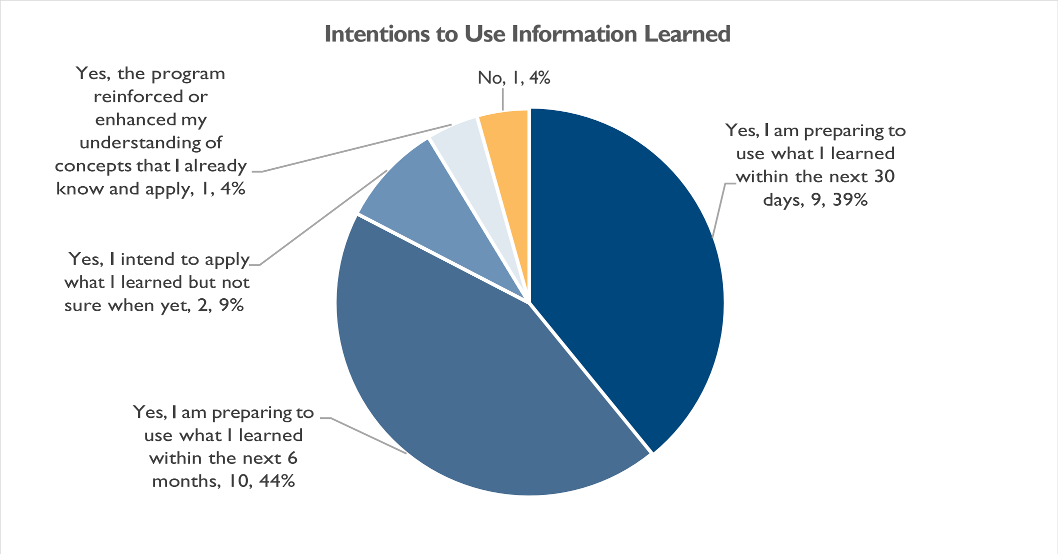


> "Thank you so much for inviting me to the PIP program -- it was truly eye-opening. I'll always treasure the stories, science, and shared moments. The experience deepened my understanding of the cancer landscape and sparked a new area of interest for me. I picked up a whole new vocabulary, connected with an inspiring mix of people, and I must say -- Adrienne's pitch really resonated. I'm now seriously considering stepping into full-scale advocacy!"
>
> – PIP participant

Other responses:

- 95% felt that they were well-matched with their science partner
- 82% connected with one or more researchers in the poster hall
- 77% said there was a good fit between the session they co-chaired and their research interests
- 73% connected with one or more CCRC/PIP supporters during the VIP lunch

Participants were also asked about how they intended to use the information that they learned while at PIP and the CCRC. Most (83%) responded that they would use what they learned within the next six months (adjacent graph).



Forty-five percent of respondents indicated that the final plenary, "Rising cancer rates in adults under 50 years" was among their top-rated sessions. "Metabolic health and cancer" was the top-rated session for 36% of respondents. This was lower for the "Immune system and cancer" plenary (23%) and "BIG data in cancer research" plenary (9%).

Camille Leahy (second from left) co-chairing the Immunotherapy concurrent with Dr. Christian Steidl (left).

> "Excellent conference! Extremely valuable that patient partners co-chaired all sessions."
>
> – Conference delegate

> "I had an amazing experience as Part of the PIP! I feel that as a newbie to the program I had to take a 'leap of faith' and jump into the unknown, then try and figure things out by being [immersed] in the program and just being present and open and participating."
>
> – PIP participant

DEBRIEF FEEDBACK

Science partners

As part of PIP, participants are paired with science partners. Science partners enable patient partners to better understand the science presented at the CCRC while PIP participants provide science partners with direct and personal experience with a person with lived or living experience with cancer. It is a mutually beneficial partnership.

Participants reported different experiences. Those who were able to connect virtually with their science partners in advance of the conference reported better experiences, which emphasizes the importance of these early connections – they enjoyed connecting at the networking event, they attended posters with their science partners, they made plans to connect/work together after the conference concluded. For those unable to attend the networking event or those for whom their science partner was unable to attend the event, the experience was not as satisfying.

Suggestions for improvements included:

- organizing a pre-conference interactive webinar/brainstorming session aimed at making the partnership more engaging
- having arranged seating with science partners for the dinner portion of the ECR networking event
- organizing a separate dinner/lunch with science partners to ensure that all participants met with their science partners
- organizing one-on-one meetings at a designated time and place (perhaps 10–20 minutes once or twice a day) to meet and chat
- developing a daily activity sheet that science partners could use to work with their participants each day to facilitate more structured discussions

Howard Dellar (right) with science partner, Dr. Zhimeng Jia (centre).

> “It was a real pleasure to participate as a science partner in the PIP. I had a great time working with my partner — there was so much to learn from each other, and I truly enjoyed the experience. I’d be delighted to be involved again if another opportunity arises.”
>
> – Science partner

Co-Chairing

As part of PIP, participants chair a conference session with a researcher. Engaging patient partners as co-chairs helps promote the value of patient engagement in research to the audience while enhancing the research advocacy skills of patient partners.

Co-chairing experiences were variable. Some reported very positive experiences – they had engaged with their co-chairs ahead of time and jointly determined how the session would be delivered. Others had only minimal advanced contact. One participant reported that she was ‘cut-off’ by her co-chair when relaying her story.

One recommendation made was that a template for co-chairing be prepared, which would outline a standard format/approach to time allocation for the concurrent sessions to ensure that patient co-chairs were provided with a predictable timeslot to make their introductory comments. This document could also clearly identify the co-chair roles. Additional training could be provided for co-chairs on how to better work with patient partners as co-chairs.

Other suggestions included surveying PIP participants in advance about the kinds of sessions they would like to co-chair and clarifying the need for a land acknowledgement at the start of the session.

Sandra Dudych (seated) looks on with co-chair Dr. Hermann Nabi (seated) as Dr. Mark Basik presents his research during the concurrent, "From Risk Assessment, Screening and Surveillance to Survivorship."

Eddy Szczerbinski moderates questions during the "Patient Experience" concurrent session.

Poster Sessions

A poster session is an interactive event at scientific conferences where many research posters (visual summaries of research) are made available so that conference delegates can speak to the researchers to gain a better understanding of their work.

There were several suggestions on how to improve the poster session experience. On the practical side, bigger labels on the poster boards and more directional signage were identified as needed.

Some felt the time allotted for the poster sessions was too short given the number of posters. Others proposed implementing a contest, whereby patient partners voted on the best lay presentations. This could be done with science partners. Additionally, the conference app could be better leveraged to include poster uploads or accessible language summaries which could be available in advance of the conference.

Randy Baldwin (right) speaks with poster presenters during the Sunday poster session.

Sundas Shamshad (right) engages with a presenter during the Monday poster session.

Conference Plenaries and Concurrent Sessions

Plenaries are main sessions held at conferences that are designed for all delegates. They highlight important and emerging research topics. Concurrent sessions are multiple presentations that take place simultaneously in different rooms. Delegates choose which sessions they are going to attend.

Many felt that the opening session or initial plenary should be more patient focused and include a roadmap on how to engage patients, the importance of patient engagement, and barriers to collaboration. Emphasizing that patient partners are there to be a resource to conference delegates was suggested. The incorporation of a patient advocate panel as a plenary was also proposed as an option to consider. Augmenting the French content was also identified as important.

Some practical suggestions for the concurrent sessions included making a portable mic available and providing a screen in front for concurrent sessions so that the co-chairs and presenters can view the slides while speakers are presenting.

Kirsten Efremov asks a question during the "Metabolic Health and Cancer" plenary.

Networking Opportunities

Conferences present a great opportunity to meet others, share ideas, and potentially build future collaborations.

PIP participants greatly valued the connections made with other patient advocates. They set-up a WhatsApp group while onsite but felt that this and the sharing of cell phone numbers could have been done in advance of the conference.

Some suggestions to increase the networking opportunities included:

- providing a structured opportunity for each participant to tell their story (10 minutes) followed by 5 minutes for QnA to help foster an understanding of each participant's advocacy efforts
- meeting at the end of the day to debrief and review the day's events and share experiences
- organizing pre-scheduled dinners to foster teamwork

PIP Participant Profiles

Mini-biographies or profiles shared during conferences help delegates to connect with one another.

PIP participants shared their profiles with one another during the online Meet and Greet sessions held during the summer. While for past CCRCs, we have added PIP biographies to the conference app, permissions were not secured from all participants in the weeks prior to the start of the 2025 CCRC.

Participant suggested:

- including a short introduction of PIP during the opening ceremony to the larger audience to describe the participants (e.g., types of cancers, geographical locations) and provide guidance about how to connect with participants

- preparing a biography template so that participants could add in their skills. There could be a QR code on their badge which could link to their bios
- sharing bios and picture of participants in advance and/or on the conference app

Conference Program

A conference program is a structured and strategic schedule that outlines the timing and location of sessions and related events. It is highly dependent on the venue and other logistics.

Participants suggested:

- avoiding scheduling sessions over the lunch break
- reinforcing that participants do not have to attend all components of PIP/CCRC – the days are very long especially for people living locally and travelling to and from the venue
- incorporating some structured exercise
- reducing the walking back and forth from the venues

Sherry Metcalfe (at podium) co-chairing the "First Nations, Inuit and Métis Stories" concurrent.

Meals/Food

Meals may/may not be part of a conference. In the case of PIP, breakfast and lunches were provided on all days of the 2025 CCRC.

Participants suggested:

- knowing in advance what meals were included, and if the meals not included could be expensed
- offering more options for those with dietary restrictions, including varied vegetarian options
- avoiding processed meats

Other Suggestions

A few additional suggestions were provided by PIP participants:

- making the font bigger on the one-page CCRC printed program-at-a-glance and using a more readable colour scheme
- having PIP mentors (previous participants) available to answer questions and describe their experience and what to expect
- providing a resource person for participants if they are triggered by topics discussed during the CCRC
- recording sessions to permit participants to view sessions that they did not attend
- taking the group photo on the first day
- assigning seating for the VIP lunch and providing suggested discussion topics (e.g., what is the most interesting thing you learned)
- ensuring appropriate use of photos/videos – concerns were expressed over photos taken of slides presented during sessions and of the cultural events

Justin Gaudet in conversation with Elder Louis Heavenfire.

Valentine Thompson (seated left of podium) listens to Dr. Paola Marignani as she presents her research during the "Environment Impacts on Cancer" concurrent.

Suad Ismail, Sundas Shamshad and Natalie Kwadrans at the VIP Lunch.

Alyssa Dickey (standing), Megan Quintal (seated) during the VIP lunch.

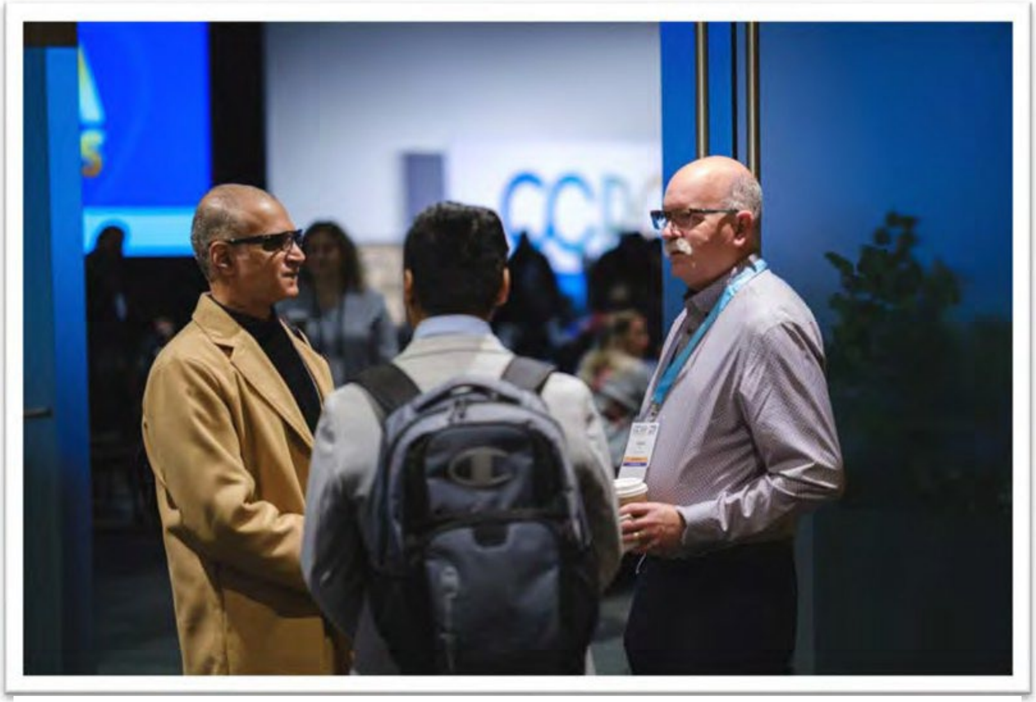
Lucy Ioannoni (left) speaks with science partner Dr. Yiming Wang (right) and Tanvi Anandampillai (centre) between the plenaries.

"I wanted to express my 'Thank you' for the opportunity to participate in PIP as science partner. It was truly a valuable learning experience to interact with some with lived experience."

– Science partner

"Being a PIP Member was one of the best experiences I have ever had. The conference was spectacular."

– PIP participant



Darrin Park (right) in conversation with Dr. Arata Matsuyama (back), science partner and another delegate, during a break.

> "I very much [enjoyed] the CCRC 2025, especially the opportunity to interact with the PIPs. It is a humbling experience to see the dedication of the patients to science."
>
> – Science partner

PROGRAM REVENUE AND COSTS

The support level was set at $4,500 per participant, with a goal to raise $108,000 in revenue, which was based on an estimate of 24 participants.

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

- significant in-kind support provided by the CIHR Institute of Cancer Research, who supported the 20 science partners and provided dinner for the PIP participants on October 31
- additional in-kind support provided by the Canadian Partnership Against Cancer for the administration and delivery of the program, financial management and the production of the two PIP-related videos
- in-kind support provided by the Alberta Cancer Foundation for the tour of the Arthur J.E. Child Comprehensive Cancer Centre on November 1

Organization	$	Type of Support
Canadian Cancer Society (CCS)	13,500.00	Directed (3 CCS Patient Partners)
Alberta Cancer Foundation	10,000.00	Directed (3 participants from Alberta)
Garron Family Cancer Centre/The Hospital for Sick Children*	9,000.00	Directed (2 participants from Ontario)
The Terry Fox Research Institute (TFRI)	9,000.00	Directed (2 participants)
BioCanRx	4,500.00	Directed (1 participant)
Canadian Partnership Against Cancer	4,500.00	Directed (1 participant)
Cancer Research Society	4,500.00	Undirected (1 participant)
Quebec Cancer Research Network (RRCancer)	4,500.00	Directed (1 participant from Quebec)
Ontario Institute for Cancer Research (OICR)	4,500.00	Directed (1 OICR Patient/Family Advisor)
Saskatchewan Health Research Foundation	4,500.00	Directed (1 participant from Saskatchewan)
Myeloma Canada	4,500.00	Directed (1 participant)
TOTAL	**73,000.00**	

**One participant was unable to attend. $4,500 will be carried forward to PIP 2027.*

Projected and actual costs are provided below. The support revenue (above) did not meet the target by nearly $20,000.

Component	Detail	Projected Costs	Actual Costs	Notes
Participant Expenses	Registrations	12,000.00	7,875.00	Actual is based on regular patient advisor registration fee of $300 plus 5% GST
	Catering	15,000.00	13,630.18	Includes catering outside that offered at the CCRC
	Airfare/travel	26,400.00	21,273.82	
	Accommodation	27,500.00	31,479.96	PIP participants from outside Calgary were reimbursed to a maximum of 5 nights
	PIP room rental	5,700.00	6,877.50	The program had its own designated room at the Telus Convention Centre
PIP General Admin	Working Committee Compensation	5,000.00	4,462.50	
	Translation and administration (e.g., certificates)	9,000.00	7,000.00	Actuals plus estimated translation costs for this report
	TOTAL	**100,600.00**	**92,598.96**	

John Corriveau (right) co-chairing the "Metabolic Health and Cancer" plenary with Dr. Josie Ursini-Siegel (left).

Chantale Thurston (seated) listens as Dr. Darren Brenner presents his research during the final plenary, "Rising Cancer Rates in Adults Under 50 Years: What do we need to know?"

PROPOSED RECOMMENDATIONS FOR THE 2027 PIP

Increase Financial Support

There is a need to look to alternate sources of support or at capping the number of participants in the program to ensure that the program is revenue neutral. Since its inception, PIP has not yet been able to secure sufficient funding to cover the program costs.

Scope Out the Impact of the French Language Requirements Introduced in 2025

The 2027 PIP/CCRC will be taking place in Montréal. There is a need to understand how Quebec's Law 14 (Bill 96) will affect program delivery.

Continue to Hone the Valued Aspects of the Program

To specifically address the feedback, future programs will work towards:

- ensuring that every participant has an opportunity to connect in person with their science partner before the start of the conference
- providing increased and formalized opportunities for participants to network among themselves and with their science partners during non-conference hours
- designing a template or standardized approach for how concurrent sessions are to run with particular focus on the co-chair roles and timing for introductions – this will need to be clearly communicated to the SPC
- structuring the VIP lunch with more intent and providing assigned seating
- improving the poster experience by developing a curated number of posters in a poster session specifically designed for PIP participants
- getting permissions to share PIP participant bios on the conference app
- offering a workshop at the CCRC on patient engagement in research that is led by participants of PIP Working Committee and supported by program participants

2025 PIP SUPPORTERS

2025 PIP SUPPORTERS • COMMANDITAIRES DU PPP 2025

CIHR IRSC
Institute of Cancer Research
Institut du cancer

ALBERTA CANCER FOUNDATION

Canadian Cancer Society
Société canadienne du cancer

INSTITUT DE RECHERCHE TERRY FOX RESEARCH INSTITUTE

SickKids
Garron Family Cancer Centre

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

BioCanRx
Canada's Immunotherapy Network
Le réseau canadien d'immunothérapie

Société de recherche sur le cancer
Cancer Research Society

MYÉLOME CANADA
MISSION : MAÎTRISER LE MYÉLOME
MYELOMA CANADA
MAKING MYELOMA MATTER

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

RRCANCER
Réseau de recherche sur le cancer

SHRF
SASKATCHEWAN HEALTH RESEARCH FOUNDATION

> "I love PIP and the idea that patients becoming more knowledgeable of cancer research makes them better advocates for all that matters to a cancer patient and their caregivers. I think this edition was absolutely brilliant and I'm sure the next will be even better!"
>
> – PIP participant