



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 2021 Virtual PIP and Recommendations for Future Programs

Contents

ACKNOWLEDGEMENTS2

SUMMARY4

BACKGROUND5

PROGRAM APPLICANTS AND PARTICIPANTS6

PIP COMPONENTS8

PROGRAM EVALUATION..... 11

FUTURE CONSIDERATIONS..... 17

PROGRAM COSTS & REVENUE..... 22

OPTIONS FOR FUTURE PROGRAMS 24

PIP 2021 SUPPORTERS 26

ACKNOWLEDGEMENTS

The 2021 Virtual PIP was made possible by the financial support of the Canadian Cancer Society, CIHR Institute of Cancer Research, Ontario Institute of Cancer Research, Canadian Partnership Against Cancer, BioCanRx, Cancer Research Society, The Terry Fox Research Institute, Alberta Cancer Foundation, Institut du Cancer de Montréal, Réseau de recherche sur le cancer (RRCancer), and the Saskatchewan Cancer Agency.

We would also like to acknowledge the patient partners who comprised this year's working group and whose leadership helped shape the 2021 program: Ms. Ruth Ackerman (Chair), Ms. Nathalie Baudais, Dr. Don Desserud, and Ms. Debi Lascelle. The most vital component of PIP is the active participation of its participants. In addition to the four working group members, the following participants of the 2021 program undertook the grant review with care and diligence and those involved as conference session co-chairs prepared and recorded thoughtful introductions: Mr. Jason Abramovitch; Mr. Mark Beck; Ms. Louise Bird; Mr. Vikram Bubber; Ms. Melissa Coombs; Ms. Kirsten Efremov; Ms. Catherine Hays; Mrs. Heather Hogan; Dr. Rosilene Kraft; Mr. David Laird; Ms. Donna Pepin; Mme Lucie Piché; Mr. Angus Pratt; Mr. Archie Stewart; Ms. Michelle Stratton; Ms. Katey Thompson; Ms. Chantale Thurston; Dr. Christine Qiong Wu; and Ms. Mei-Lin Yee. Their active participation is what makes PIP, PIP!

Twenty-three science partner volunteers helped to support patient partners to understand the science being presented during the CCRC. They were: Mr. Javad Alizadeh (University of Manitoba), Dr. Arshad Ayyaz (Mount Sinai Hospital), Dr. Versha Banerji (University of Manitoba/CancerCare Manitoba), Dr. Armin Gamper (University of Alberta, Cross Cancer Institute), Dr. Victoria Hoskin (Queen's University), Mr. Danyyl Ippolitov (University of Manitoba), Mr. James Jeon (University of British Columbia), Mr. Kyle Lewis (McGill University), Dr. Ali Mahdipour-Shirayeh (University of Toronto), Mr. Elias Maldonado (McGill University), Mr. Kyle Malone (CHEO Research Institute), Dr. Paola Marignani (Dalhousie University), Mr. Daniel Medina-Luna (Dalhousie University), Dr. Arvind Singh Mer (Princess Margaret Cancer Centre), Dr. Alli Murugesan (University of New Brunswick), Dr. Véronique Ouellet (CR-CHUM), Dr. Sarah Poynter (Wilfrid Laurier University) Dr. Ambreen Sayani (Women's College Hospital), Dr. Hsien Seow (McMaster University), Ms. Noor Shakfa (Queen's Cancer Research Institute), Ms. Kiersten Thomas (BC Cancer), Dr. Florence Anjong Tikum (University of Saskatchewan), and Dr. Michael Witcher (The Lady Davis Institute of McGill University).

Four keynote and 15 concurrent session co-chairs worked with patient partners to introduce and moderate the CCRC sessions. They were: Dr. David Dawe (CancerCare Manitoba, University of Manitoba), Dr. Brenda Elias (University of Manitoba), Dr. Lynn Gauthier (Centre de recherche du CHU de Québec, Université Laval), Dr. Shashi Gujar (Dalhousie University), Dr. Timothy Hanna (Queen's University), Dr. Claudia Kleinman (McGill University, Lady Davis Institute), Dr. Madhuri Koti (Queen's University), Dr. Elena Kuzmin (Concordia University, McGill University), Dr. Madeline Li (University Health Network, Princess Margaret Cancer Centre), Dr. Paola Marcato (Dalhousie University, Beatrice Hunter Cancer Research Institute), Dr. Rachel Murphy (University of British Columbia), Dr. Martine Puts (University of Toronto), Dr. Jacques Simard (Centre de recherche du CHU de Québec, Université Laval), Dr. Erin Strumpf (McGill University), Dr. Nawaid Usmani (University of Alberta), Dr. Franco Vizeacoumar

(Saskatchewan Cancer Agency, University of Saskatchewan), Dr. P. Peter Wang (University of Toronto), Dr. Gareth Williams (University of Calgary), and Dr. Amina Zoubeidi (University of British Columbia).

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 virtual format for PIP and she worked to ensure that PIP participants were well-profiled on the conference platform and supported in their co-chairing role. Other pivotal support was provided by staff of the Canadian Partnership Against Cancer: Mr. Kris Atterbury, Specialist, Production and Design, produced the PIP and PIP grant promotional videos; Mr. Timothy Ellis, Coordinator, Research and Innovation, provided ongoing editorial and technical support; Ms. Jessie Yin, Controller, and Ms. Holly Yao, Senior Accountant, managed the in-flow and out-flow of supporter contributions and program expenses; Ms. Shirley Dong, Manager, Finance and Partner and Vendor Services and Ms. Crystal Bhandari, Contract Analyst, executed the agreement for the PIP grant.; and Ms. Luna Andraos, Consultant, French Translation/Project Management, supported the program's translation needs, often working under tight timelines.

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 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

“We live on hope and hope is research.”

– PIP Participant

Like all world events, the pandemic affected delivery of our third **Patient Involvement in Cancer Research Program (PIP)** and the program was re-configured into a virtual format as part of the 2021 Canadian Cancer Research Conference (CCRC). The program was attended by 23 patient partners and supported by 11 Canadian Cancer Research Alliance (CCRA) member and affiliated organizations.

Of the 19 participants completing the post-program evaluation, all indicate that the PIP was worth their time to attend. Most participants felt the program had relevance and applicability to their research advocacy and rated the various components as valuable. Among conference delegates responding to the post-CCRC online survey, there was increased familiarity and interest in involving patients in cancer research, indicators that the cancer research community is increasingly recognizing the value of patient engagement.

New to the 2021 PIP was the introduction of a grant competition. This was a small grant opportunity targeted to trainees and early career investigators. It was adjudicated entirely by PIP participants—they had full control of rating the applications and determining the final grant winner. This experience was considered the most valuable to participants and had the added advantage of helping to cultivate group rapport, an important bonus in a virtual environment.

Of note, there was substantial variability in the participant experience. An in-person format creates a feeling of sharedness that is hard to re-create in the virtual environment. While PIP participants who had participated in previous programs felt that an in-person experience provided much more value in terms of networking, it is noteworthy that some of the new recruits indicated that they would not participate in an in-person event. To ensure inclusivity and heed the preferences of all patient partners, a hybrid model would be an important consideration moving forward and a few options are proposed on how this could be accomplished.

Lessons learned from the virtual experience indicate the need to embed more patient-patient interactions and patient-researcher interactions during the scheduled conference. In addition, better preparation of both science partners and session co-chairs is needed to ensure that these program components are optimized. Finally, virtual posters need to be better constructed to improve patient partner usability and facilitate interactions between poster presenters and PIP participants.

The interest in PIP – as demonstrated by the record number of applications – suggests that, despite a growing number of opportunities for patient engagement in research, there is an ongoing need for PIP. Plans are underway with the CIHR Institute of Cancer Research to pilot a “PIP Lite” in 2022 to see how more patient partners can be engaged in scientific fora outside the CCRC. These efforts will likely build on the CCRA’s patient engagement goals and broaden the number and skill levels of Canada’s cancer patient research advocates.

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 Key to the 2021 program was the move of the Canadian Cancer Research Conference (CCRC) to a virtual format necessitated by the pandemic and the introduction of a PIP grant competition, a decision made by the CCRC Executive Planning Committee (EPC) in spring 2021. A report on the 2021 CCRC will be released shortly.²

Planning for an entirely virtual event with the addition of a grant competition required additional work prior to the CCRC start date, although in terms of total workload required, it was offset by the 24/7 demands inherent in an onsite event. Lessons learned from the face-to-face programs were not all applicable in the virtual context.

Strong commitment by CCRA member organizations to patient engagement is evidenced by ongoing support for the program, which was easily acquired. In addition, the continued interest in PIP by past program participants is also indicative of its value and success.

KEY ABBREVIATIONS

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

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.

In this report, we have interspersed screenshots of PIP participants from the virtual CCRC, which captures their vibrant presence during this event.



Dr. Jacques Simard and Ms. Nathalie Baudais, co-chair the Keynote session, “Understanding and Managing Risk – The saga of hereditary cancer.”

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

²This report will be posted to <https://www.ccra-acrc.ca/conference/past-conferences/>.

PROGRAM APPLICANTS AND PARTICIPANTS

The call for applications to the program was made on June 29, 2021. The program was promoted on the CCRA website, via the CCRA Twitter account, 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 July 23, 2021.



Mr. Archie Stewart co-chairs the concurrent session, "Lifestyle and Diet."

APPLICANTS

A target of 25 participants was determined for the 2021 program, five more than the 2019 program. A total of 52 applicants were received by the deadline, nearly double what was received in 2019. It is believed that growing awareness of the importance of patient engagement in research in addition to the virtual format offering were contributors to program demand.

Of the 52 applicants, most were women (44/52) and over half were in the age range of 50-69 years (28/52). Over one-third were from Ontario (19/52). Many had been diagnosed with breast cancer (16/52) and lung cancer (11/52), the latter being due to promotion through the Lung Cancer Canada network. Very few were caregivers only (3/52) and most rated their research experience in the mid-range – i.e., some familiarity/some involvement in cancer research activities/projects/priority setting (33/52).

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). In some cases, support was specific to patients. Twenty-five applications were selected, but two participants opted out for health and personal reasons and, due to time constraints, these vacancies were not filled. It may be important to stipulate upfront that the program may not be right for people undergoing active treatment.



Ms. Michelle Stratton co-chairs the concurrent session, "Patient Engagement."

PARTICIPANTS

The following page provides a demographic summary of the 23 participants for 2021 PIP. This was not only the largest participant cohort to date for PIP, but the most diverse group in terms of age groups, gender, geography, and cancer experience.

2021 Virtual PIP: Snapshot of Participants (N=23)



Good Morning from Québec !

Lucie Piché, Lucie Piché

	Age range				TOTAL
	19-33	34-49	50-69	70+	
Women	1	4	10	1	16
Men	0	2	3	2	7
TOTAL	1	6	13	3	23

Perspective*	Participants
Cancer patient/survivor	21
Cancer patient/survivor & caregiver	1
Caregiver	1
TOTAL	23

One person identifies as Indigenous, three as visible minorities, and four indicated that they have a disability.

Province	City/town size				TOTAL
	Large centre	Medium centre	Small centre	Rural	
AB		1			1
BC	3				3
MB	3				3
NB			1		1
NL	1				1
NS			1		1
ON	5	1	1		7
PE			1		1
QC	1		1		2
SK	1		1	1	3
TOTAL	14	2	6	1	23

Definitions of Locations by Population Size

(Statistics Canada)

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

Cancer	Time since Initial Dx			TOTAL
	Less than 5 years	5 to 10 years	More than 10 years	
Appendix	1			1
Blood		2		2
Brain		1		1
Breast	1	2	5	8
Childhood			2	2
Colorectal	2			2
Lung	1	2	1	4
Ovary			1	1
Thymoma			1	1
Multiple			1	1
TOTAL	5	7	11	23

Self-rated Experience level	N
No involvement in cancer research	5
Some familiarity/some involvement	16
Extensive involvement	2
TOTAL	23



David from Winnipeg

David Laird, retired

PIP COMPONENTS

Working Group

Unlike previous PIPs, this year's program was directed by a working group comprised of four patient representatives, all of whom had previously attended PIP. Ms. Ruth Ackerman was the Chair of the working group. Ruth participated in both the 2017 and 2019 programs and has been a patient representative on the CCRA Board since January 2018. Dr. Don Desserud, the other patient representative on the CCRA Board (since January 2020), was the second group member. Don participated in the 2019 PIP. Ms. Nathalie Baudais and Ms. Debi Lascelle, experienced patient research advocates, both of whom had attended PIP in 2017 and 2019, rounded out the group.

Ruth and Don, given their roles on the CCRA Board, were also members of the CCRC EPC, which provided oversight and logistical advice for the CCRC, and which was chaired by Mr. Patrick Sullivan. Nathalie and Debi served on the CCRA Scientific Planning Committee (SPC) alongside co-chairs, Drs. Franco Vizeacoumar and Martine Puts, and other researchers. The SPC spearheads the development of scientific content by identifying novel session themes, chairs, and speakers, and overseeing abstract review and selection.

The working group provided invaluable direction, support, and feedback in terms of the program format and the process and materials related to the PIP grant. In addition, Don, Nathalie, and Debi helped to create videos on PIP, which were aired during the CCRC and helped to inform conference delegates about the program and elevate the patient profile.³ Ruth helped to create the promotional video on the PIP grant with the PIP grant winner, Dr. Stéphanie Bernard.⁴

In terms of the CCRC itself, all four members were co-chairs for the Keynote sessions at the CCRC (one Keynote session was held on each day of the CCRC). Nathalie did double-duty by co-chairing the concurrent session, "Cancer Clinical Trial Approaches."

Program Components

Program components are outlined in the table below. Two Meet & Greet sessions



Dr. Don Desserud co-chairs the opening keynote session, "Personalizing Big Data."



Ms. Debi Lascelle speaks to the merits of PIP and patient engagement in research in this video presented at the CCRC.

³These videos are now available on the CCRA website at <https://www.ccra-acrc.ca/about-us/patient-involvement/>.

⁴This video is available at <https://youtu.be/2TY305YwJbU>.

(each 90-minutes) were held on September 15 and 20. Participants provided brief biographies that were circulated in advance of the sessions.

Participants were then paired up to undertake review of the grant applications (more details about the PIP grant opportunity are provided below). The concept of working in dyads was suggested by the working group and was helpful in facilitating the review and building group rapport.

Most participants were assigned to be co-chairs for the conference keynotes sessions (as noted above) and the concurrent sessions. As co-chairs, they were responsible for recording introductory videos and for attending their sessions during the scheduled timeslot.



Ms. Melissa Coombs and Dr. Timothy Hanna, co-chair the "COVID-19 and Cancer Screening and Treatment" concurrent session.

All participants were assigned a science partner. Science partners are researchers and trainees who identified an interest in working with a patient partner during the submission of their abstract to the CCRC. There were 99 such abstract submitters who noted that they were interested in working with patient partners. Of these, 22 were selected as they best matched to program participants based on the patient partners' research interests. One participant's science partner was from the organization that supported her attendance at PIP.

The patient-science partner partnership is two-fold and reciprocal:

- 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 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.

Although this year's program was virtual, patient partners and science partners from past programs indicated that these partnerships were a very valued component of the PIP learning experience.

In addition to participating in the CCRC (held from November 8 to 11, 2021), participants were able to review the session recordings and posters on the platform after the conference, which many did.

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.



Ms. Kirsten Efremov fields questions during the "Bioinformatics and AI" concurrent session.

PIP Grant

The PIP grant was an inaugural funding opportunity pilot tested as part of the 2021 PIP at the suggestion of the EPC. A single one-year grant for \$15,000 was offered for trainees and early career investigators to support a project that included a patient engagement element.

Grant guidelines and an application form were created. The latter was a fillable PDF with prescribed sections, designed so that the identifiers could be stripped from the applications to facilitate a blinded review process. A blinded review process was identified as an important means to level the playing field for all applicants. The application form was not onerous and focused on the essential elements of the proposed project and the anticipated outcomes/benefits for patients. The grant guidelines detailed the rating criteria and general process for the grant evaluation.

The opportunity was launched on the CCRA website on August 23, 2021 and subsequently promoted via the CCRA Twitter account, the CCRC distribution list and by CCRA member organizations. We were fortunate that the Canadian Centre for Applied Research in Cancer Control (ARCC network) also promoted this opportunity for us. Applications were due on September 22, 2021.

Nineteen applications were received. Most applicants (11/19) were working at institutions in Ontario. There was a mix of qualifications: 3 Masters candidates, 5 Doctoral candidates, 7 postdoctoral fellows/residents, and 4 early career investigators.

The applications were evaluated by PIP participant dyads in blinded reviews. Each PIP participant dyad reviewed five applications and each application was reviewed by three dyads (i.e., six participants in total reviewed each application). Applications were evaluated on four criteria using 5-point rating scales. The maximum possible score was 60 points.

Evaluations were completed on October 8, 2021. Scores ranged from 31 to 57, with an average score of 44. The three top-rated applicants were selected to proceed to the online presentation phase of adjudication.

Each of the three top-rated applicants presented to PIP participants in 30-minute online sessions held on October 18 and 19, 2021. These sessions allowed patient partners to request additional information from applicants and provide feedback to the applicants. Applicants also addressed PIP participants' questions in emails submitted after the sessions. Participants submitted individual ratings by October 21, 2021. They then met as a group on October 25 to discuss the ratings and select the winner. Results were as follows:

PIP Grant Adjudication Results

Applicant	Title	Round 1	Round 2	Round 3
Dr. Stéphanie Bernard, University of Alberta <i>*Winner</i>	Exploring gynecologic cancer survivorship needs, barriers and facilitators to virtual pelvic health care: a patient-centred multi-methods study	95%	81%	88%
Dr. Bre-Anne Fifield, University of Windsor	Empowering cancer patients: a pilot project to create a community engagement program to drive patient engaged research	93%	77%	85%
Dr. Maclean Thiessen, CancerCare Manitoba	Optimizing recruitment for patient engagement: an extension of ongoing work to enhance patient engagement at CancerCare Manitoba	90%	74%	82%

Dr. Bernard, the competition winner, is a post-doctoral fellow at the University of Alberta in the Faculty of Rehabilitation – Physical Therapy. The Canadian Partnership Against Cancer, as the fiscal agent for CCRA/PIP, executed the grant agreement with the University of Alberta on December 20, 2021. As part of the terms of the grant, Dr. Bernard will present the results of her research at the CCRA Annual Members' Meeting in late November 2022.

PROGRAM EVALUATION

Observations and feedback on the 2021 PIP was collected from a number of sources: the online post-CCRC delegate (bilingual) survey (QuestionPro); an online post-PIP questionnaire (bilingual) for PIP participants (QuestionPro); two 90-minute group debrief session with PIP participants (held on December 19 and 20, 2021); individual calls with PIP participants (held mid-December); feedback from science partners (optional; via email); and PIP grant applicants (optional; via email, calls, and online meetings).

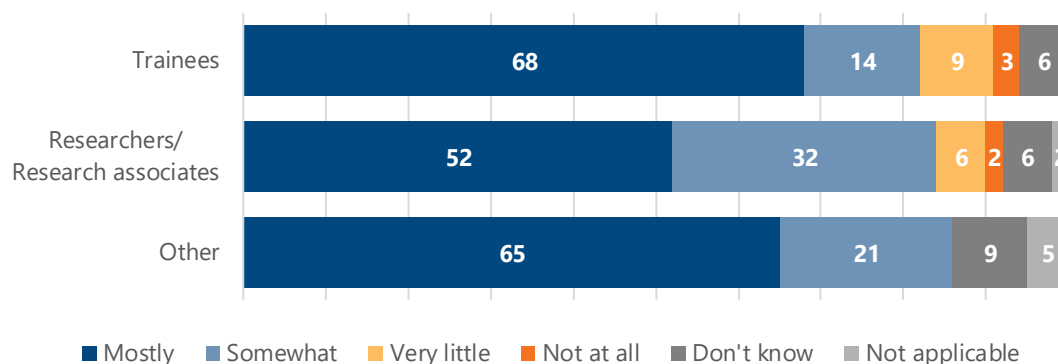


Ms. Ruth Ackerman congratulates PIP grant winner Dr. Stéphanie Bernard in a promotional video shown during the CCRC.

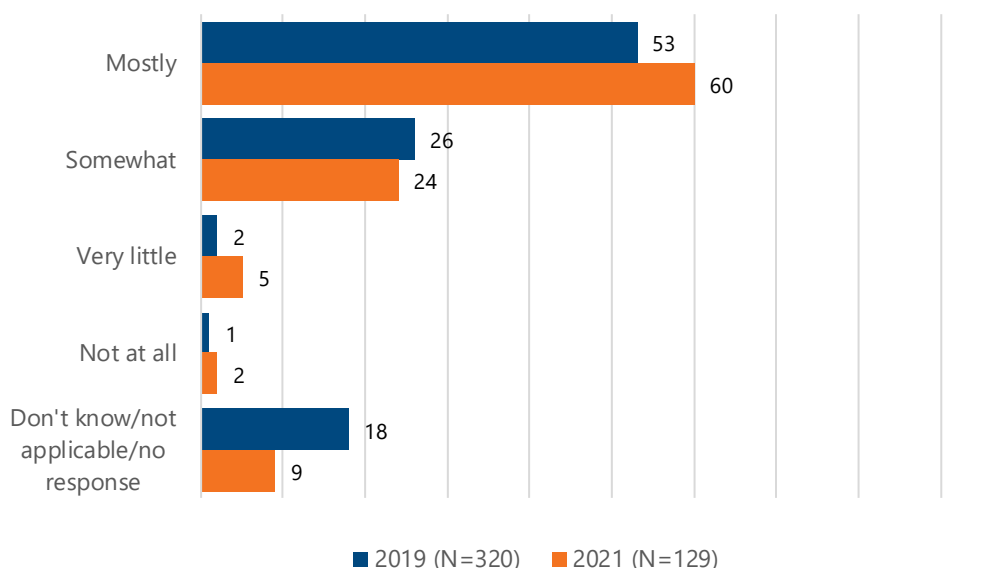
Post-CCRC Delegate Survey

The post-conference delegate survey was completed by 129 people. More than half of respondents, regardless of role, felt that the conference objective related to patient involvement was achieved—a higher proportion than was reported for the 2019 program.

Extent to which conference objective, "Enhance patient involvement in cancer research in Canada" was achieved, % of 2021 CCRC survey respondents (N=129)



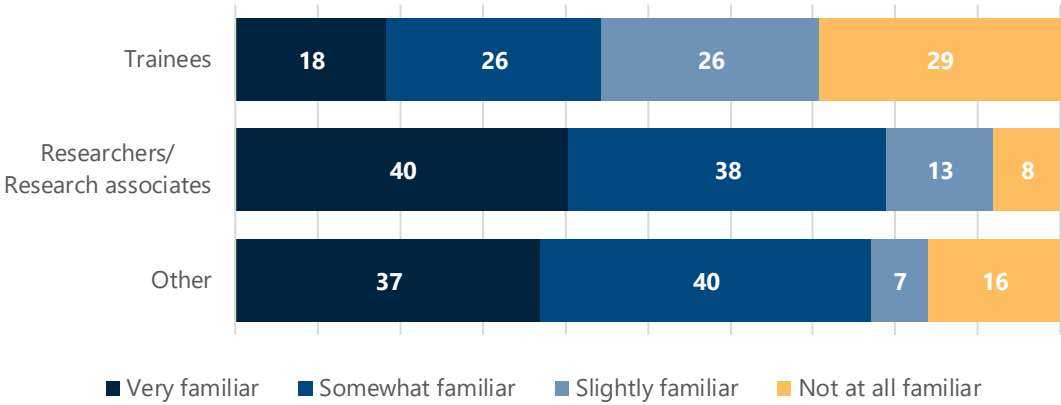
Extent to which conference objective, "Enhance patient involvement in cancer research in Canada" was achieved, 2019 and 2021 (%)



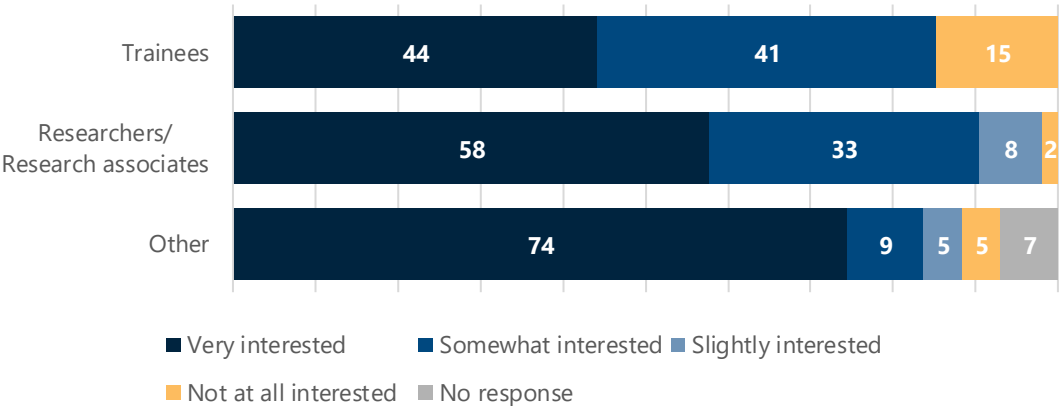
Familiarity with including patients and/or caregivers in research to help decide research priorities was highest among researchers/research associates while interest in involving patients and/or caregivers as research partners was highest among the 'other' group, which included clinicians, patient advisors, and delegates from the charitable sector and industry. The proportion of respondents indicating high familiarity and interest on these two dimensions has almost universally increased since 2017.

One in four respondents indicated that patient involvement was a factor influencing their participation in the CCRC and 34 survey respondents indicated that they had networked with a patient partner on the virtual conference platform.

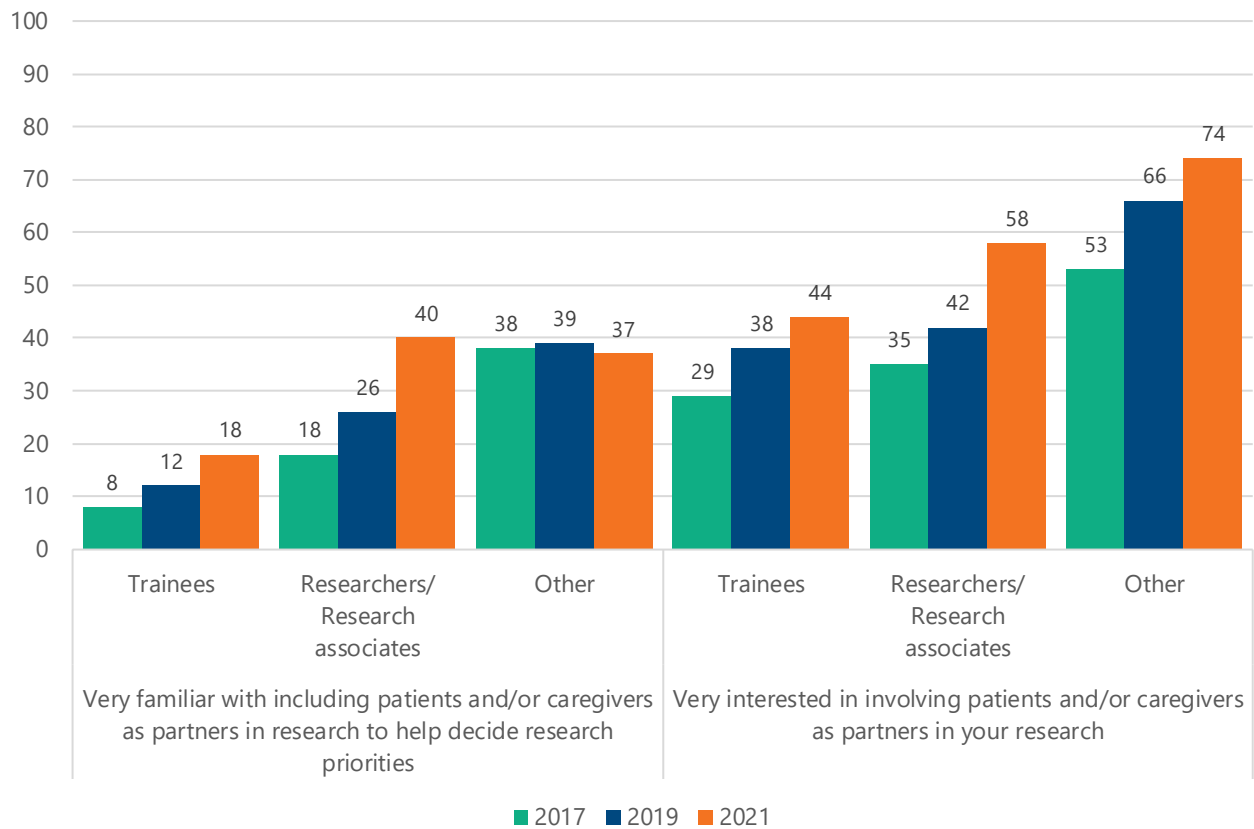
Familiarity with including patients and/or caregivers as partners in research to help decide research priorities, % of 2021 CCRC survey respondents (N=129)



Interested in involving patients and/or caregivers as partners in your research, % of 2021 CCRC survey respondents (N=129)



Comparison of survey respondents (%), 2017, 2019, and 2021



Ms. Donna Pepin and Dr. Lynn Gauthier, co-chair the "Patient Reported Outcomes and Patient Experience" concurrent session.

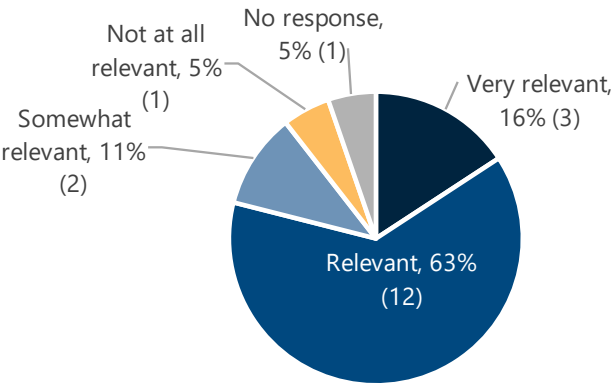
Post-PIP Participant Questionnaire

Nineteen of the 23 PIP participants completed the online questionnaire. All respondents felt that participation in PIP was worth the time invested. Most (15/19) felt that the information presented during PIP/CCRC was relevant/very relevant to a challenge that they were currently facing. Somewhat fewer respondents (12/19) felt the information presented during PIP/CCRC was applicable/very applicable to them.

The PIP Grant adjudication was rated to be a very valuable component of the program for most participants. There was variability in the perceived value of working with session co-chairs.

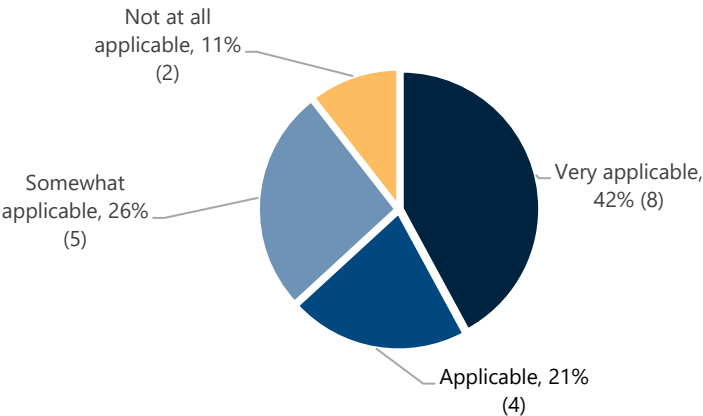
While the Keynote sessions tended to be perceived as valuable to respondents, the concurrent sessions rated as most valuable were: "Equity in Cancer Care;" "Patient Engagement;" and "Lifestyle and Diet." Lightning sessions were less likely to be rated as valuable, with the one exception being "Palliative Care." Most respondents planned to use the information presented at PIP/CCRC in their patient advisory/advocacy activities and many planned to share the information learned with others.

Relevancy of the information presented at the PIP/CCRC to a challenge that you are currently facing (N=19)



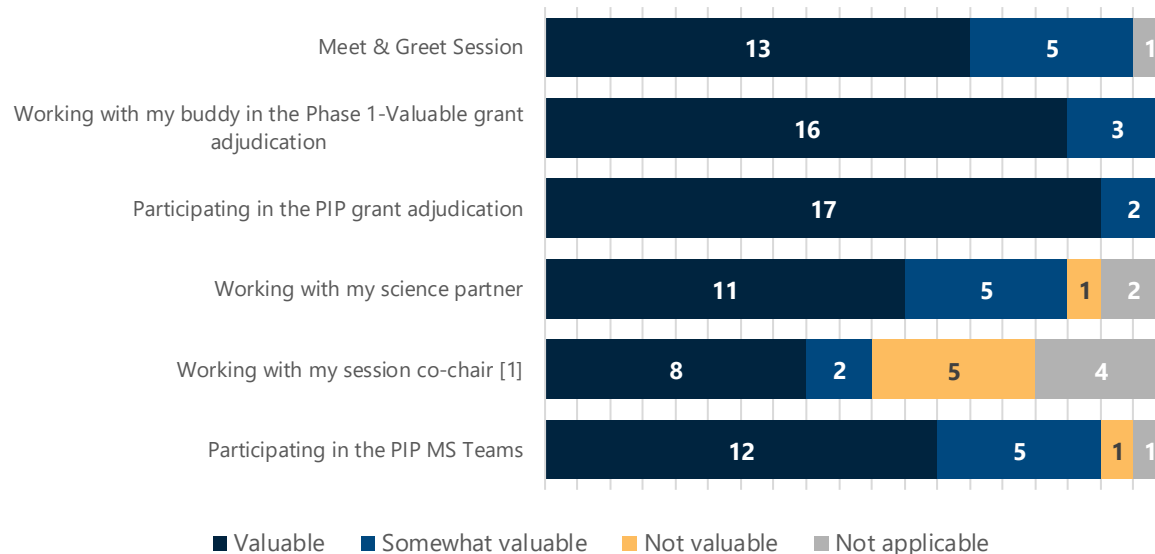
Ms. Louise Bird opens the concurrent session, "Indigenous Cancer Research."

Applicability of the information presented at the PIP/CCRC to you (N=19)




Ms. Chantale Thurston poses questions during the concurrent session, "Immunotherapy."

Value of Program Components (N=19)



[1] 18/23 PIP participants were session co-chairs.



Catherine Hays

I've had a long journey with cancer. My mother died from metastatic breast cancer when I was a young child. I still remember my mother's illness – her coughing up blood, the hospital bed in the downstairs bedroom, her tears when she read stories to me. I also remember the day she died. I am not alone with these memories as mothers are still dying, every day.

My first bout with cancer was when I was 26 – a dermatofibrosarcoma, then breast cancer at 46 and metastases diagnosed at 64. I have cancer in my thoracic cavity, lungs, pleura and liver. I just recently passed my tenth year of living with mets. Ten years of experience. I am luckier than most, since most live three to five years.

I remember the gurus saying that "one day metastatic breast cancer would be a chronic condition," which translated into "just how lucky we would be." And I do admit, it has a lot more appeal than dying. But no one ever mentioned the toxic load that would build after years of therapies or maybe I just didn't want to hear. No one ever mentioned the unrelenting fatigue, the aches and the nausea; frail and breaking bones. There is also neuropathy, toxicity, severe bone pain, mental stress, which so many metastatic patients endure. And for many of our sisters and brothers worldwide, there is also the inability to receive treatment, or financial toxicity.

Dr. Amina Zoubeidi presents Ms. Catherine Hays' moving introduction during the Metastasis concurrent session.

OTHER FEEDBACK

The drawbacks of virtual conferences have been widely documented. With a patient population, there are additional considerations such as internet connectivity in rural areas. It is recognized that by the next CCRC in 2023, there will likely be increased functionality and innovations in virtual meeting platforms. We have elected not to enumerate the technical challenges that participants reported as these were varied and will not likely have relevance for future events.

Most PIP participants felt that the PIP videos, patient co-chair recordings, and inclusion of the patient profiles presented on the conference platform helped heighten the patient presence at the CCRC. PIP participants who had attended the program previously (in person) were most likely to feel a loss of the patient-patient interactions and reported that, with a virtual event, it was harder to convey their commitment to making a difference to researchers. In addition, some of those who worked while attending the CCRC found the virtual format a difficult balancing act given a lack of dedicated focus. On the flip side, some felt a compulsion to view all the session recordings, even while recognizing that at an in-person event, there would trade-offs in terms of what could be attended.

The French language issue persists. It is challenging to accommodate francophone patient partners in what is a largely an English forum.

FUTURE CONSIDERATIONS

Expand opportunities for participant-participant interaction

- Use an ice breaker at the Meet & Greet sessions
- Offer more opportunities for virtual networking/social time during the CCRC. This could take the form of daily online touchpoints, "working lunches," etc.
- Hold webinars through the year to keep the PIP participants engaged
- Offer ongoing virtual checkpoints – e.g., coffee chats every 3 months
- Re-institute the preparatory science workshops as part of the PIP curriculum

Improve the participant-researcher networking experience

- Assign patients on a random basis to break-out rooms and provide an opportunity for researchers to ask patients questions. Alternatively, provide a Q&A panel with researchers and

WHAT WE HEARD

"Overall, the CCRA Conference was a meaningful experience. I continue to feel an 'Awe' and 'Wow' when I listen to many of the scientific presenters knowing that their expertise is genuinely focused on the improvement of outcomes for cancer patients." – PIP participant

"The conference was well organized with a breath of scientific topics. The patient involvement made it very interesting and real." – Conference delegate

"Despite the new virtual format, I enjoyed attending CCRA this year. Connecting and contributing as the Science Partner is my most exciting new experience."
– Science partner

WHAT WE HEARD

"The program made patients feel as important as the researchers. We were heard and respected." – PIP participant

"Connecting with other people with advanced cancer across Canada helps you to feel less isolated." – PIP participant

"I'm humbled and so proud that CCRA is doing patient engagement and encourage them to engage more AYAs." – PIP participant

PIP participants, where researchers can ask patient partners about their experiences and research priorities – this can be an environment where the patients are the specialists

Streamline program communications for patient partners

- Provide a better overview of the program components – i.e., grant review and conference
- Prepare a step-by-step guide to the grant review process
- Streamline email communications with a master document available in one centralized place that lists all timelines, instructions, documents, and deadlines

Enhance the co-chairing experience

- Ensure co-chairs connect before the CCRC – a call beforehand is absolutely needed. A structured meeting with all co-chairs may be a means to facilitate this
- Clearly communicate co-chairing expectations – provide guidelines on roles and scope to assure a more standardized approach (e.g., how to handle questions and answers)
- Develop a question bank that can be used by patient co-chairs
- Provide relevant terminology in advance to help patient co-chairs better prepare
- Explore the feasibility of sharing presenters' recordings and/or slide decks in advance with patient co-chairs



Ms. Mei-Lin Yee leads the Q&A during the concurrent session, "Equity in Cancer Care."



Dr. Christine Wu and Dr. Elena Kuzmin, co-chairs of the "Precision Medicine and Biomarkers" concurrent session.

Strengthen the partnership between patient partners and science partners

- Start contact earlier; hold a session with patient partners and science partners before the conference
- Institute a structured format for engaging patient and science partners – e.g., end of day 'debriefs' to keep the momentum going, virtual lounge on the conference platform
- Explore ways to facilitate this partnership post-CCRC (that being said, this has occurred and has also been the case for co-chairs)
- Include science partners in the post-program patient partner debriefs

Improve poster access⁵

- Improve the poster hall search engine
- Ensure poster presenters have 'office hours' to encourage more timely interaction with patient partners. This could be facilitated via a curated list of posters prepared by the PIP coordinator that are based on participants' interests
- Provide a special session on posters for PIP participants – this could be based on common themes of interest (e.g., patient engagement, survivorship research, palliative care)



Mr. Angus Pratt leads the Q&A component of the "Metabolism" concurrent session.

WHAT WE HEARD

"One of the most enjoyable parts for me has been my interaction with the young researcher that I was assigned. Not only was she an excellent scientific translator but she dragged me into sessions that I might not have ordinarily chosen. Lest this appear to be a one-way street, I did the same thing to her. I found it easy to encourage her to ask questions in the sessions too - which she thanked me for."
– PIP participant

"There was value in working with the science partner. He didn't understand the patient viewpoint and I didn't understand the science jargon, so hopefully there was reciprocal benefit." PIP participant

"I have tremendous respect for the PIP program of CCRA that provides the valuable opportunity for researchers to work closely with patient partners and gain broader perspectives...It's my pleasure to contribute to a program that stands close to my heart. Thank you." – Science partner

"The topics of interest of my patient partner intrigued me and gave me the better sense of the most important scientific problems and the needs of patients. I quite loved the lived experiences shared, and the practical questions posed by the patient partners that co-chaired the CCRC sessions. PIP helps me see the bigger picture of my scientific research pursuit. I would like the partnership made now to grow beyond the CCRC conference." – Science partner

"PIP is a valuable program for researchers at all stages." – Science partner

⁵Poster presentations are recognized to be among the biggest "casualties" of virtual conferences (Spears V. Reflections on the upsurge of virtual cancer conferences during the COVID-19 pandemic. *BJC* (2020) 123:698–9; <https://doi.org/10.1038/s41416-020-1000-x>).

Facilitate the interpretability of the scientific content

- Embed lay-friendly content – e.g., provide guidance to speakers on what is appropriate for a lay summary and more explanations of key terminology
- Ensure every presentation, especially basic science ones, addresses how the research will help patients
- Engage patients as panelists/speakers
- Utilize more real-time/live sessions, including debate formats. Live and robust Q&As were considered very important.
- Limit the number of concurrent events – longer/fewer sessions were preferred
- Explore the feasibility of adjusting (slowing) the speed of recorded sessions. In particular, lightning sessions were presented quickly and were difficult to follow.

Tweak the PIP Grant opportunity

For a first-time effort, the PIP grant was a resounding success. Working in dyads helped patient partners to recognize the challenges in adjudicating and it had the added benefit of building group rapport. Applicants indicated that the PIP grant filled an important need as there are only a limited number of small grant opportunities available. The guidelines were considered helpful, and applicants appreciated that the rating scheme was fully disclosed.

Future considerations:

- Promote the opportunity more widely (e.g., hospital research institutes, Canadian Association of Genetic Councillors, patient engagement organizations, medical schools, schools/faculties of nursing, social work, rehabilitation, etc.)
- Offer separate opportunities for trainees and postdoctoral fellows/early career investigators. Timelines and grant stipends could be adjusted accordingly.
- Increase the time between the call and the submission deadline (at least 2-3 months) to facilitate engagement of patient partners in the proposed research and ensure institutional approval can be arranged
- Build in flexibility on the one-year grant timeline – one year may be tight, especially with the pandemic; 18 months would be helpful and build in a cushion to accommodate ethics review

WHAT WE HEARD

"It's the first Canadian general cancer conference I attended. I didn't expect it to be so exciting!!!" – PIP participant

"This was my first PIP and my first conference. While at times I felt overwhelmed by the science and the terminology of it all, the conference and the information shared regarding the amazing research being undertaken resulted in four days well spent." – PIP participant

"The session recordings are a great resource. I have gone back and get more from each viewing." - PIP participant

WHAT WE HEARD

"I loved the PIP grant review. I had a great partner and we learned from one another." - PIP participant

"The grant review helped build bench strength for patient partners to be involved in the grant review process going forward." - PIP participant

"In my view, the review process was a success, and it clarified several points/doubts for me. Comparing my experience in the grant review committee of ASCO Conquer Cancer Foundation in this type of grant, our review is, by all means, as good as ASCO's reviews." - PIP participant

- Look at instituting a more fluid model, with small pools of funds that are rolling/flexible and are offered outside the CIHR cycle
- Expand the preparation/training for patient partners – e.g., holding a simulation seminar, including information on research costs (e.g., open access publishing costs)
- Offer a pre-grant information session on patient engagement in research for interested applicants
- Clarify the grant focus - immediate/short-term benefit vs long-term/innovative research. Should the selection criteria consider projects that might not get funding funded elsewhere?
- For the adjudication process, align grant ratings with specific sections of the application form. Improve the organization of forms/files so that ratings can be expedited.
- In terms of the application form, move away from a fillable PDF to a word document or Google document, with page limits and/or word counts. Add an extra section to permit a description of the value of engaging patients in the application and how patients are contributors to the project (distinction between participants vs partners). Allow the inclusion of a brief CV.
- Share the patient feedback and ratings with all applicants. If possible, consider including these directly on the application form that could then be returned to the applicant.
- In terms of the online session (second phase for top-rated applicants), increase the time between notification and scheduling to permit more time to prepare. Have a smaller group of patients involved in the online session and use part of the time for brief introductions.
- In terms of the guidelines, add a description of what patient engagement is and more references. Provide more precision in terms of timelines for the online presentation, especially how post-online session emails are to be incorporated. Ask applicants to clearly address if and how patient partners will be remunerated.
- Explore the feasibility of doing the two-step adjudication in the reverse order - initial proposal as an online presentation with questions/answers followed by written submission for the top-rated presentations.



Dr. Rosilene Kraft introduces the concurrent session, "Epigenetics."



Mrs. Heather Hogan poses questions to presenters in the concurrent session, "Tumour Microenvironment and Immunology."



Ms. Katey Thompson introduces the concurrent session, "Imaging and Radiation Oncology."

PROGRAM COSTS & REVENUE

Budget estimates were presented to the EPC in July 2021. Members decided to roll the PIP grant into the per participant PIP/CCRC program costs. A rate of \$1,500 per participant was determined to ensure revenue-neutrality.

The table below shows the amounts of support provided by each organization.

WHAT WE HEARD

"I commend the fee waiver to the science partners. It made me feel appreciated and responsible." – Science partner

"Thank you very much for reimbursing the conference fee in recognition of my high score in the PIP competition. This is very much appreciated!" – Grant applicant

Organization	\$	Type of Support
Canadian Cancer Society	6,000.00	Undirected
CIHR Institute of Cancer Research	6,000.00	Undirected
Ontario Institute of Cancer Research	6,000.00	Directed (4 participants from Ontario)
Canadian Partnership Against Cancer	4,500.00	Directed (3 Patient/Family Advisors)
BioCanRx	3,000.00	Undirected
Cancer Research Society	3,000.00	Undirected
The Terry Fox Research Institute	3,000.00	Undirected
Alberta Cancer Foundation	1,500.00	Directed (1 participant from Alberta)
Institut du Cancer de Montréal	1,500.00	Directed (1 participant from Quebec)
Réseau de recherche sur le cancer (RRCancer),	1,500.00	Directed (1 participant from Quebec)
Saskatchewan Cancer Agency	1,500.00	Directed (1 participant from Saskatchewan)
TOTAL	37,500	

Projected and actual costs are provided in the table on the following page.

Component	Detail	Projected Costs	Actual Costs	Notes
Program-related	CCRC registration (\$310 + HST x 25 patient partners)	7,750.00	7,410.92	Regular registration fee for Researchers applied.
	CCRC registration (\$85 x 25 science partners)	3,085.00	4,791.71	Feedback from 2019 PIP supported 1:1 ratio of patient partners to science partners. Estimates were based on early-bird registration fees for 13 Trainees (\$85) + 12 Researchers (\$165). NB: Costs for science partners in PIP 2019 was provided by CIHR through the ECI program (~\$22,800 registration + travel/accomm).
	Translation	1,250.00	1,525.36	French translation costs for participant support materials, evaluation report (estimated), etc.
	Working Group recognition & related postage		414.03	
	Participant certificates of completion & related postage		110.52	
	Video production			In-kind support provided by the Canadian Partnership Against Cancer
	Financial management of support dollars and program expenses			In-kind support provided by the Canadian Partnership Against Cancer
PIP Grant	PIP Grant Amount (no overheads)	15,000.00	15,000.00	Fixed; single grant; one-year term
	Legal agreement (Partnership-Institution)	3,000.00	4,004.44	One-time legal fees for contract set-up between Partnership and grant recipient's institution. In-kind support provided by procurement & vendor services at the Partnership
	Translation	4,000.00	1,216.21	French translation costs for grant application guidelines, application form, adjudication, agreement, etc.)
	Honorarium support for application review	1,500.00	0	As needed; dependent on application pressure; past PIP participants paid to review applications (\$25/hr)
	CCRC registration fee waived for grant winner and two runners-up		929.76	
TOTAL		35,585	35,404	

OPTIONS FOR FUTURE PROGRAMS

There seems to be consensus in the literature that virtual science conferences will continue after the pandemic and, for PIP, virtual events do open the door to broader, more inclusive patient engagement. Technological advancements will undoubtedly make future virtual events more seamless, interactive, and meaningful.

Hybrid models have been touted as the path forward and they do have promise in the patient engagement space, although they are still plagued with the problems of virtual meetings – namely, digital burnout, time zone issues, and larger issues of internet connectivity for rural locales. More importantly, hybrid events are more expensive – requiring extra staffing resources and the additive costs of technology/virtual platforms as well as venues/catering associated with virtual and face-to-face meetings, respectively.

Some experts have suggested that our notion of hybrid events as occurring simultaneously be decoupled and that virtual events could take place over a longer time span (e.g., a series of 3-4 smaller-scale, brief events organized to showcase regional expertise or research relevant to a specific cancer type or discipline) and culminate in a larger in-person event. A subscription model could be used to offset some of the costs of this serialized approach.

The dyad model for grant review was very successful and demonstrated that with refinements this program component can continue to be executed virtually. While the success of the PIP grant may lead us to consider an expansion of this program, it is important to recognize that the impetus was to create a learning opportunity for patient partners, with the secondary benefit of supporting patient engagement research. CCRA as a collective entity is not in the business of grantmaking and the CCRA Executive Office does not have the staff resources to undertake a major expansion this program. That there is a need for small and flexible grant funding opportunities geared to trainees and early career investigators as highlighted by applicants is an important consideration for CCRA members as they formulate their own grant-making opportunities. If an expansion is desired, it is suggested that one competition be maintained with targeted focus and that the top two or three applicants be awarded monies.

The table below provides some potential options for consideration and further discussion by CCRA members. The approximated costs are based on the following assumptions:

- 24 participants (in the hybrid concurrent, there would be 12 virtual and 12 in-person; hybrid serial option would have 24 participants for the virtual events and 12 for the in-person conference)
- one-to-one matching with science partners – all science partners would have their registration fee waived regardless of event type, but their travel/accommodation would not be covered for in-person
- there would be one grant competition
- in-kind costs (communications, translation, grant agreement execution, program coordination) would continue to be assumed by the Partnership/CCRA Executive Office

Costs for the hybrid models are very crude estimates, which would require further refinement if a decision was made to pursue one of these options. In addition, covering the travel/accommodation costs for science partners would add substantially to the in-person and hybrid expenses.

Event type	Estimated Program Costs - Range	Approximate cost per participant – 1 PIP grant winner @ \$15K	Approximate cost per participant – 3 PIP grant winners @ \$20K
Virtual	\$38,400-\$96,000	\$1,600	\$4,000
Hybrid - concurrent	\$96,000-\$144,000	\$4,000	\$6,000
Hybrid – serial	\$120,000-\$156,000	\$5,000	\$6,500
In-person	\$144,000-\$192,000	\$6,000	\$8,000

PIP 2021 SUPPORTERS



Canadian Cancer Society
Société canadienne du cancer



CIHR
IRSC

Institute of
Cancer Research
Institut du
cancer



OICR / IOIRC

Ontario Institute
for Cancer Research

Institut ontarien de
recherche sur le cancer



CANADIAN PARTNERSHIP
AGAINST CANCER
PARTENARIAT CANADIEN
CONTRE LE CANCER



Canada's Immunotherapy Network
Le réseau canadien d'immunothérapie



Société de recherche
sur le cancer
Cancer Research Society



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



Alberta Cancer
FOUNDATION



INSTITUT
DU CANCER
DE MONTRÉAL

