



PIP

PATIENT INVOLVEMENT IN CANCER RESEARCH PROGRAM

Evaluation of the Inaugural Program held in Vancouver from November 4-7, 2017
and Recommendations for Future Programs

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ACKNOWLEDGEMENTS

The PIP was made possible by the financial support of the CIHR Institute of Cancer Research and following organizations (in alphabetical order): Alberta Cancer Foundation, BioCanRx, Brain Tumour Foundation of Canada, Breast Cancer Society of Canada, Canadian Cancer Clinical Trials Network, Canadian Partnership Against Cancer, Fonds de recherche du Québec - Santé, Ontario Institute for Cancer Research, Quebec Breast Cancer Foundation, Prostate Cancer Canada, Saskatchewan Cancer Agency, and The Terry Fox Research Institute.

We would also like to acknowledge the members of the steering committee who helped plan the program – Ms. Cathy Ammendolea, Mr. Barry D. Stein and Mr. Patrick Sullivan – and the four scientific mentors – Drs. John Bartlett, Paul McDonald, Jennifer O’Loughlin, and Kelley Parato.

Presenters for the tailored PIP session included: Dr. Gerald Batist, Ms. Niya Chari, Dr. Lynne-Marie Postovit, Dr. Stephen Robbins, Mr. Barry Stein, and Mr. Patrick Sullivan. A special thank you to Ms. Diana Ermel for editing the PIP handbook.

And finally, the success of this inaugural program was largely due to the inspired perseverance of Mr. Patrick Sullivan and the active participation of the 14 individuals who diligently attended an action-packed program, interacted with researchers, and generously provided their ideas on how the program could be improved going forward.

SUMMARY

The inaugural Patient Involvement in Cancer Research Program (PIP) was held from November 4 to 7, 2017 in Vancouver, BC. The program was attended by 14 patients/caregivers and supported by 13 CCRA member organizations. Four mentors volunteered their time to assist participants to navigate the science presented during the conference.

Participants rated the program as worthwhile and all were able to identify a specific learning/insight that was useful to their own lives and/or advocacy work at five weeks post-program. In terms of program improvements, several were generated with the most frequent focused on enhancing the profile of patients during the Canadian Cancer Research Conference (CCRC), improving the accessibility of the scientific poster presentation sessions, and augmenting the frequency of patient-scientist interactions.

Several recommendations for future programs are identified as well as cost implications of these modifications/additions. This report will be used to inform Canadian Cancer Research Alliance (CCRA) members and the 2019 CCRC Executive Planning Committee on their decision-making regarding continued patient involvement.



PIP 2017. From left to right - back row: Helene Hutchings, Denis Raymond, Kelley Parato, Jennifer O'Loughlin, Ruth Ackerman, Debi Lascelle, Greta Hutton, Patrick Sullivan, Kathy Brooks, Roberta Casabon, Diana Ermel, Johanne Marcoux, Kim Badovinac. Front row: Heather Douglas, Paul McDonald, Zeba Tayabee, Michelle Bell, Marie-France L'Italien, Nathalie Baudais. Missing: John Bartlett, Judy Needham.

BACKGROUND

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

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

The Scientific Program Committee (SPC), chaired by Drs. Gerald Batist, Shoukat Dedhar, and Christine Friedenreich, was committed to developing a conference program to incorporate the patient voice. Gerry invited Ms. Cathy Ammendolea and Mr. Barry Stein to join the SPC. Cathy, a breast cancer survivor and the current Chair of the Board of Directors for the Canadian Breast Cancer Network (CBCN), works with a variety of organizations to ensure that the patient perspective is used to inform breast cancer decision-making. Barry, a survivor of metastatic colon cancer, is the long-time President of Colorectal Cancer Canada and a vocal advocate for policy change to improve the lives of cancer patients.

Members of the SPC also felt that some sessions within the scientific program would benefit by having patient chairs and co-chairs. To this end, one of the three plenaries had a patient co-chair and five of the 25 concurrent sessions had a patient chair/co-chair/presenter. In addition, a patient presentation by Ms. Dodie Katzenstein was included in the Celebration of Science public lecture.

The EPC also felt that CCRA should add a new award to its existing awards program to recognize exceptional leadership in patient involvement in cancer research and the call for nominations in April 2017 included this new award category. (One PIP participant and one clinician would go on to receive this new award.)

Furthermore, the co-chair of the EPC, Dr. David Huntsman requested, in the spirit of bidirectional learning, that a readings list on patient involvement in research be compiled for conference delegates. This list, prepared by the Executive Office, was made available to delegates on a USB key and on the conference app, alongside the scientific program and abstract books.

A patient-specific curriculum and handbook were also developed by the Executive Office to help prepare participants for the conference. Ms. Diana Ermel, past patient representative on the CCRA Board, assisted in editing the handbook.

The CCRC online delegate evaluation questionnaire distributed after the conclusion of the conference contained items that would provide baseline measures on delegates' familiarity with patient oriented research and their interest in involving patients in their research.

Although the program developed rather organically over the course of nearly 18 months, its components (summarized on the next page) do show a broad and integrated approach to patient involvement for this inaugural effort.

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

CCRA	Canadian Cancer Research Alliance
CCRC	Canadian Cancer Research Conference
CIHR	Canadian Institutes of Health Research
EPC	Executive Planning Committee
SPC	Scientific Program Committee

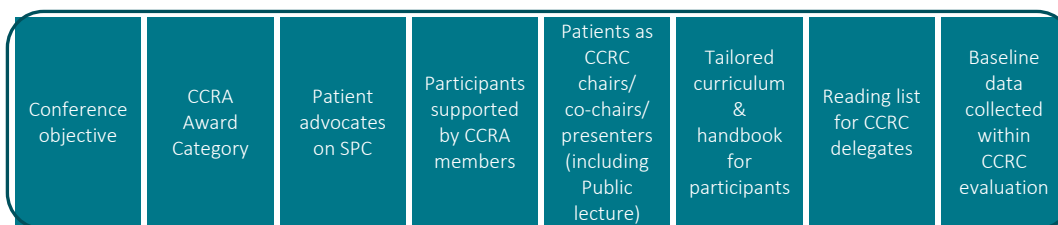


Figure 1. CCRA's approach to patient involvement in 2017



Judy Needham accepts her CCRA Award for Exceptional Leadership in Patient Involvement in Cancer.

PIP: PLANNED VERSUS ACTUAL

Participants

Fifteen applications were received for the program from CCRA member organizations and affiliates. One participant was too ill to attend and the application was withdrawn; another was deemed medically unable to travel two weeks before the program, but the sponsoring organization found a replacement. Thus, there were 14 participants for the inaugural program (see Figure 2 below), which was within the original target of 8 to 15 participants set during the program planning process.

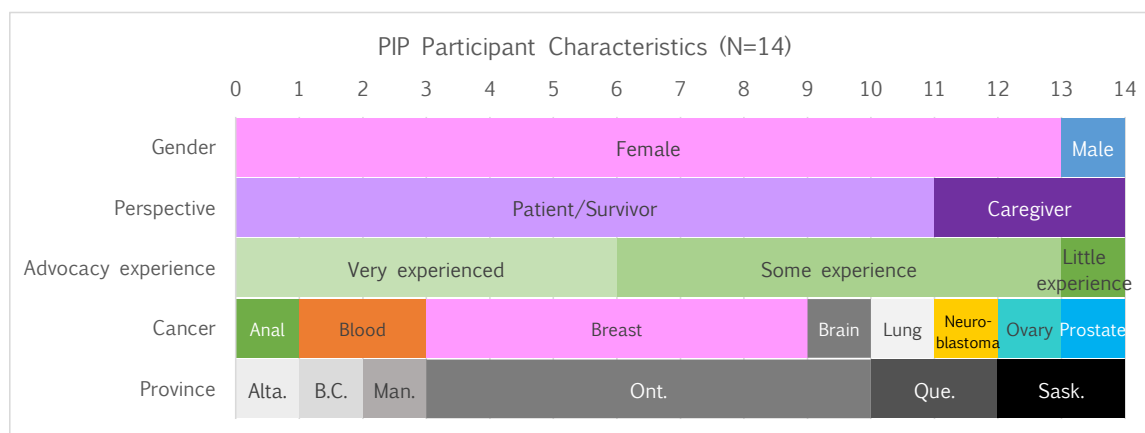


Figure 2. Summary of PIP participant characteristics

Participants registered themselves using the online registration portal. Travel and accommodation arrangements for all participants were made by the Executive Office.

Program

The PIP consisted of tailored sessions and touch points within the scientific conference with scientific mentors (see Figure 3 below in pink) as well as all components of the CCRC (teal). Participants were also invited to attend a dinner with participants of the Early Career Research Program on Friday evening prior to the start of the program (blue). This was an optional event.

OPTIONAL	DAY 1	DAY 2	DAY 3	DAY 4
Dinner with participants of the Early Career Research Program	PIP Overview Advocacy 101 Cancer Research 101 Networking Dinner	Plenary & Concurrent Sessions Science Q&A Poster Viewing & Networking	Plenary & Concurrent Sessions Science Q&A Poster Viewing & Networking Public Lecture: Celebration of Science	Plenary & Concurrent Sessions Science Q&A PIP Feedback Session Program Closure

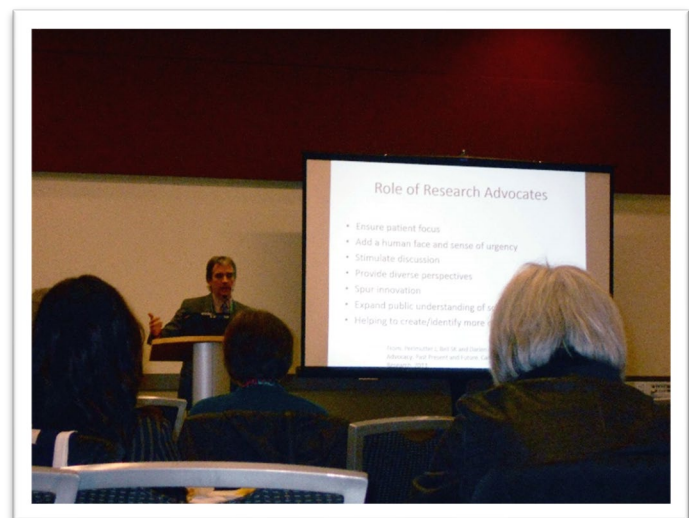
Figure 3. PIP agenda

Mentors functioned as the conduit between the scientific program and PIP. They were there to help PIP participants navigate the scientific conference and to answer arising questions about the science that participants were exposed to during the plenaries and concurrent sessions (during the Science Q&A noted in the above agenda). The four mentors spanned all four pillars of research:

- Dr. John Bartlett, Director, Diagnostic Development, Ontario Institute for Cancer & Provincial Principal Investigator, Ontario Tumour Bank [Clinical pillar]
- Dr. Paul McDonald, Staff Scientist, Integrative Oncology, BC Cancer Agency [Biomedical pillar]
- Dr. Jennifer O'Loughlin, Professor, School of Public Health, Université de Montréal [Health systems and health services & Social, cultural, environmental, and population health pillars]
- Dr. Kelley Parato, Director, Scientific Affairs, BioCanRx [Biomedical/translational pillar]

Although participants were free to attend any of the concurrent sessions offered, the following were recommended to them:

- A3. Reviewers' Choice: Top Abstracts from the 4 Research Pillars or A5. Canadian Indigenous Populations and Cancer
- B3. Impactful Canadian Clinical Trials or B4. Pediatric Oncology or B5. Tobacco, Cancer, and Control



Patrick Sullivan provides an overview of research advocacy during the Saturday session.

- C4. Strategies to Personalizing Cancer Care: Putting the Patient First or C5. Occupational and Environmental Risk Factors and Cancer or C6. Canadian Partnership for Tomorrow Project
- D1. Mechanisms of Metastasis or D4. Prevention and Cancer Control or D5. “Big Data” Initiatives: Insights from the Canadian Centre for Applied Research in Cancer Control
- E1. Celebration of Science or E2. Decision Making in Cancer: Evolving Perspectives

A handbook created for PIP was distributed to participants on October 24, 2017 – ten days before the program. This handbook covered a variety of topics related to cancer research and had links to other relevant resources of interest to patients.

PROGRAM COSTS

Originally, costs were forecasted to be in the range of \$25,000-\$35,000 for an anticipated 8 to 15 participants. The actual expenses totaled about \$5,000 more and this was attributed to additional food costs. The PIP represented approximately 5% of the total expenses for the 2017 CCRC.



Debi Lascelles, sponsored by the Terry Fox Research Institute and the CIHR ICR, poses with her hero.

EXPENSES		NOTES
Airfare	\$12,733.44	Airfare for 13 patients and 1 mentor was arranged by CCRA Executive Office. 1 mentor and 1 patient were from BC. Airfare for 1 mentor included in “Other”. Airfare for 1 mentor included in CCRC speaker budget.
Accommodation	\$11,826.18	Includes hotel costs for patients and mentors were not covered through CCRC.
Meals	\$8,074.10	Costs for Saturday night dinner (TFRI dinner) were higher than per diem rate. Terry Fox Research Institute (TFRI) had its dinner scheduled for the same time as the Saturday PIP networking dinner. TFRI graciously permitted PIP participants and mentors to attend this dinner so that the group could remain together for this social event. PIP program also had additional catering costs on Saturday and Tuesday. The optional dinner of the Early Career Researchers’ Program was attended by six participants and the two CCRA Board patient/family representatives. These costs were covered by CIHR ICR.
Other	\$7,481.61	Three patients did not submit expense claims for their expenses. Amount includes honorarium for handbook editing.
TOTAL	\$40,115.33	

OBSERVATIONS, FEEDBACK & BASELINE DATA

Sources

The program was evaluated in the following ways:

- A brief paper-based questionnaire on the relevancy and applicability of the information presented (N=14) was completed at the end of the program. This data allowed PIP to be compared on like indicators with other initiatives of the Canadian Partnership Against Cancer.
- A dotmocracy exercise to rate the top sessions of the CCRC from the patient perspective (N=14) was also completed at the end of the program. This was designed to assess the meaningfulness of the scientific sessions to the patients and help in future planning.
- A group debrief, with participants, two mentors, CCRA Board patient/family representatives, Barry Stein, and Stephen Robbins (N=20), was held at the conclusion of the program to gather immediate impressions and insights on the program as well as suggestions for improvements.
- Individual phone interviews with all participants, scientific mentors, and one CCRA Board patient/family representatives (N=19) were conducted five weeks after the program to gather lasting insights. Four structured questions were used to guide the discussion with the participants: What was your most significant learning? What do you hope to do with the information you learned as a result of attending the program? How could the program improve the interaction between patients and scientists? What other suggestions do you have for improving the program for the next go-round?
- The online conference evaluation questionnaire, which was sent to all delegates to complete, included specific items related to patient involvement in cancer research. These data serve as benchmarks of delegates' awareness of and involvement in patient-oriented research.

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



Michelle Bell, sponsored by the Saskatchewan Cancer Agency and the CIHR ICR, rates her top CCRC sessions.

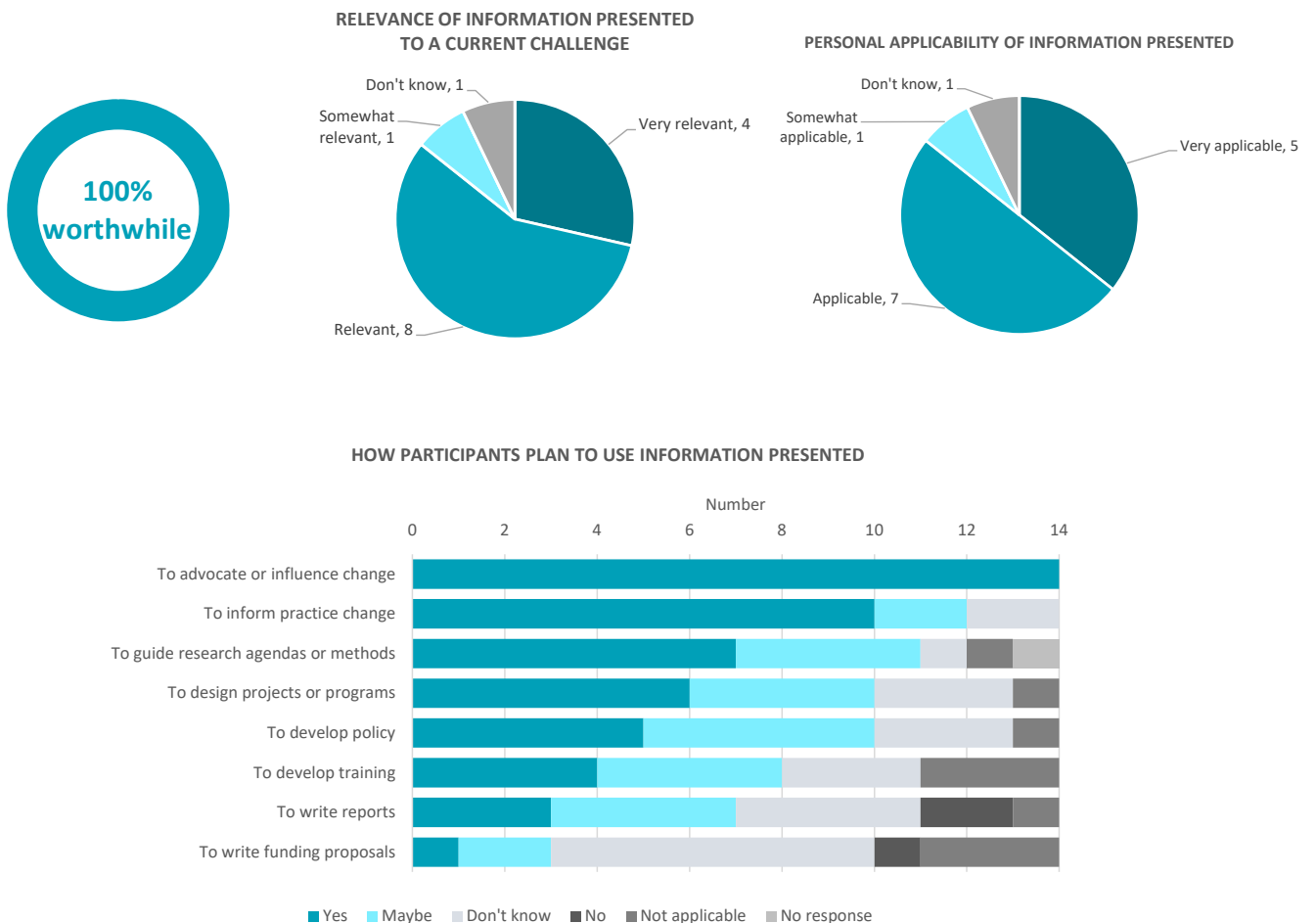
Results from Paper-based Questionnaire

The questionnaire contained four forced-choice items and one open-ended comment field. The first item was whether attendance at the PIP/CCRC was worthwhile. All participants indicated that it was worthwhile. Most reported that the information presented was relevant to a current challenge they were facing and found that the information presented was personally applicable. In terms of how they planned to use the information, all participants indicated that they would use it to advocate for change, while at least half of participants also felt that that they would use the information to guide practice change and/or guide research agendas/methods. Results are summarized below.



“Thank you for the opportunity and to have taken the time to debrief and listen to comments. The program is great and I wish you will continue to invite patients to CCRC to bring the patient perspective and make sure scientists realize that at the end of their research there is a patient.”

Marie-France L'Italien



Dotmocracy – CCRC Ratings

Participants were asked to place dots on their top five sessions within the scientific program (70 responses – 14 participants with 5 dots per participant). Results are summarized below.

SESSION	#	DETAIL
C4 – Strategies to Personalizing Cancer Care: Putting the Patient First	11	Recommended stream
Plenary Session: Metabolism and Cancer*	10	Required
E2 – Decision Making in Cancer: Evolving Perspectives	6	Recommended stream
A4 – From Bench to Clinic – Generating Evidence to Support Policy and Practice	5	
A5 – Canadian Indigenous Populations and Cancer	5	Recommended stream
Plenary Session: Cancer and the Immune System	5	Required
Plenary Session: The Burden of Cancer	4	Required
D3 – Innovative Clinical Trial Design	4	
D4 – Prevention and Cancer Control	4	Recommended stream
Poster Sessions & Exhibits	4	
B3 – Impactful Canadian Clinical Trials	2	Recommended stream
B5 – Tobacco, Cancer, and Control	2	Recommended stream
C3 – Emerging Fields: The Microbiome and Relevance to Cancer	2	
D1 – Mechanisms of Metastasis	2	Recommended stream
D6 – Marathon of Hope Lectures: Terry Fox Research Institute: Celebrating 10 Years!	2	Recommended stream
B1 – The Immune Microenvironment in Tumour Growth/Metastasis	1	
C5 – Occupational and Environmental Risk Factors and Cancer	1	Recommended stream

*The Metabolism and Cancer plenary included a presentation on the effects of weight loss on cancer biomarkers.

Group Debrief

All participants actively contributed to the debrief discussion held after the CCRC had concluded. In addition to feedback on the program, the following anecdotes were shared about some of the patient-scientist interactions that occurred during the program:

- One participant was asked to provide advice to researchers at a BC lab and help them prioritize their research directions.
- Another participant was approached by a researcher to help write a lay abstract.
- During one of the poster sessions, a participant who was experiencing drug side effects spoke about her experience to a young researcher who was doing basic research on that same drug. The researcher said “I will always remember you,” as this was her first direct encounter with a patient and it reinforced to this participant the value of the lived experience.
- One participant learned about a behavioral treatment that was described in a poster presentation, which was applicable to her own work.

The feedback that participants, mentors, and contributors shared is summarized in bullet points below and has been organized topically.

CCRC Content

- Continue to involve patients in the planning of the scientific program
- Add a Psychosocial stream – e.g., symptom management; AYA population, survivorship
- Provide more clinical content in the plenaries
- Blend with other events – e.g., “TFRI dinner was very inspiring”
- Provide more time for poster sessions
- Integrate related posters in the same location as relevant sessions

- Make the patient presence more evident – e.g., open the CCRC with patient story, have a patient story in each session, have patient co-chairs for each session, show patient video vignettes throughout the conference
- Add a patient panel
- Hold round table discussions with junior, mid-, and senior scientists to see how patients can be engaged in their research projects



Participants vote during the group debrief.

Scientific Program Book

- Add a symbol beside each session to indicate how technical it is
- Add lay or graphical summaries for each session
- Allow researchers' access to patients' profiles – i.e., include on the app or use shortened versions within the scientific program [*would need permissions from patients a priori]

PIP Session and Handbook

- Increase the number of patient participants
- Hold an introductory webinar ahead of time
- Add a session to the PIP curriculum on the science of effective ways to engage scientists
- Formalize the intersection between PIP and ECR programs – e.g., dinner first night; poster session next night. Attendees gave very positive feedback about the ECR dinner – especially about the focused process used for introductions and the set-up for the meal itself (small plates/food stations), which was designed to encourage networking. It was suggested that a meeting with participants before the ECR dinner would help them to be connected beforehand.
- Have inaugural participants as “advocacy” mentors for the next program and set-up this buddy system before the program commences
- Have advocacy mentors along with scientific mentors host a session on how to effectively integrate the patient into the scientific process
- Augment the number of scientific mentors and ensure that mentors attend all sessions that PIP participants attend (patients could be paired 1-1 with ECR participants)
- Allow patients to do their own posters and assist in the production/costs of the posters
- Augment PIP handbook content – i.e., Immunotherapy 101 (PD-1-PDL-1), Proteomics 101, and Hallmarks of Cancer in non-scientific language, how patients become involved in research, how researchers identify and engage patients, list of targeted drugs (www.mycancergenome.org), patient group pathways to clinical trials, cancer drug implementation committees, patient values in HTA, global action for cancer patients, biologic generics, i.e. mab, inhib, ets; add definitions for genotype vs phenotype, stochastic event, real world evidence

- Permit use of the handbook for broader distribution

Logistics

- Add rest periods
- Put short 5-minute breaks between adjacent sessions to enable delegates to get to the rooms
- Permit only 3 concurrent sessions per block
- Call attention to distinctive name tags and make the PIP wording bigger
- Ensure water is provided in the meeting room (none provided in room used on Saturday)
- Provide more information on how to submit expense claims
- Continue to offer healthy meals and accommodate dietary needs
- Continue to provide travel and hotel arrangements
- Consider flexible options for program financing – i.e., one patient asked if patients could pay on their own to attend PIP

Other

- Add a tour of a local lab
- Provide one place on the web to consolidate/summarize Canadian discoveries and information relevant to patients and include a patient blog

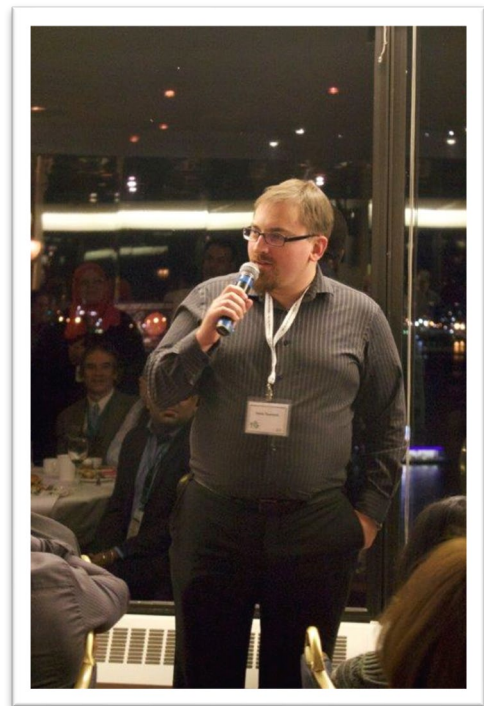
Individual Phone Interviews

There was overlap with some of the ideas shared during the group debrief. Participants continued to feel that attendance at the program was positive and worthwhile. One patient exclaimed that it was a major life event and another felt privileged at having been able to attend. Participants reported a newfound appreciation for the scientific process and observed that researchers seemed legitimately interested in the patient perspective. Some reported feeling re-invigorated to continue their advocacy work – in the words of one patient, “I have more awareness of what it means to be a cancer researcher and I’m a better advocate because of the program.”

Many felt that meeting and networking with other PIP participants was a critical factor to the program’s success. As one participant stated, “a cohesive group was created despite the fact that participants were very different people, with different motivations and even language.” More opportunities for participants to connect before the program, in informal ways throughout the program, as well as after the program were identified as ways to enhance patient-to-patient networking.

The value of the ECR networking dinner was re-emphasized during the interviews. As one participant commented, “I would see familiar faces from the ECR dinner throughout the conference, and it helped to feel more connected.” Those who attended appreciated the casual atmosphere and the opportunity to speak with young researchers.

Participants had different opinions about the content of Saturday’s tailored session, but were fairly unanimous on the need for better time management, shorter talks with more opportunities for questions/answer, and a more structured approach to introductions. There was one suggestion



Denis Raymond, sponsored by the Brain Tumour Foundation of Canada and the CIHR ICR, introduces himself at the ECR dinner.

that the session start in the morning to permit more breaks and some downtime before the evening event.

The need to balance engagement without burning out participants was a recurrent theme. One suggestion was to schedule 60-minute PIP sessions at the same time as some of the concurrent sessions within the scientific program. The PIP sessions could focus on topics like personalized medicine or immunotherapy and could be structured to allow more time for questions.

More touch points with scientific mentors, more structure to the debrief sessions with mentors, and an increased number of scientific mentors were also identified as important. One of the mentors suggested having at least three mentors from each research pillar (12 mentors). Another suggested pairing senior and junior scientists within the mentor pool. Of note, mentors did not feel that their involvement was onerous. The interactions between participants and mentors were viewed as mutually beneficial.

One participant described a program of the Alamo Breast Cancer Foundation called the “Hot Topic Mentor Sessions” as a possible model for debriefs. In this program, 90-minute sessions with a panel of experts are convened at the end of each day of the annual San Antonio Breast Cancer Symposium. The panel reports on the most intriguing, valuable and/or controversial research presented during the conference on that day and then take questions from the audience.

One of the mentors felt that the term “mentor” was an inappropriate label and urged another descriptor to better reflect the shared learning process that occurred. Another emphasized the importance of educating the scientific community on the role that advocates could play.

Increased visibility of patients was another recurrent theme (also noted during the group debrief session). Adding patient introductions was felt to be an important way to communicate the financial and emotional tolls of cancer. The concurrent D1, co-chaired by Dr. Ann Chambers and PIP participant Ms. Nathalie Baudais was identified as an important example of how the patient story could be used at the front end of a scientific session. Nathalie’s story had a profound effect on the audience and the scientific presenters, exemplified by these two tweets from attending



Heather Douglas, sponsored by the Alberta Cancer Foundation and the CIHR ICR, provides her feedback during the group debrief.

researchers: “Every scientific session at a disease specific conference should start with a patient advocate telling their story” (Kevin Bennewith); “Very touching reminder by Nathalie Baudais on why we perform research and the importance of translation to the clinic” (Nicole Wilkinson). It should be noted that Ann fully embraced the patient co-chair concept by connecting with Nathalie early on and involving her in working group meetings and session planning.

The one major challenge for all participants was the poster presentation sessions. Many found the sessions too short and felt daunted by

the sheer number of posters. Participants also reported having difficulties finding relevant posters and observed that many young researchers struggled to explain the relevance of their research to cancer patients and to communicate in non-scientific language. A better orientation to the poster sessions was needed. One participant suggested that it would be useful to target 1 to 3 researchers who could explain their posters in detail to patients and address patient questions. Another suggested curating the five best posters for specific cancer sites relevant to the patients and holding a general QnA session between those poster researchers and PIP patients. One of the mentors felt

that the mentors themselves could help patients navigate the posters by attending one poster with participants. Relatedly, another suggested that mentors could provide patients with a tour of the posters to help orient them. Enhancing the map of posters and using plain language descriptions to group posters were two additional recommendations to enhance the poster presentation experience.

Mentors and participants alike felt that there was a need to keep the momentum going. Looking for ways to keep the PIP participants engaged and connected as well as ways to outreach to the scientific community, specifically to young scientists, was identified as important. A webinar for researchers on benefits of engaging patients at different stages in the research process would be useful.

On the plus side, mentors did not feel that participation was onerous and that covering registration and costs would be attractive to prospective mentors. One mentor suggested that mentors could be identified within the online abstract system by providing a description of the mentor role and remuneration.

And finally, providing more opportunities to acknowledge the PIP supporters was identified as crucial to sustaining the program.



Zeba Tayabee, Kathy Brooks, Diana Ermel, Paul McDonald, and Greta Hutton during the group debrief.

Baseline Data from CCRC Delegates

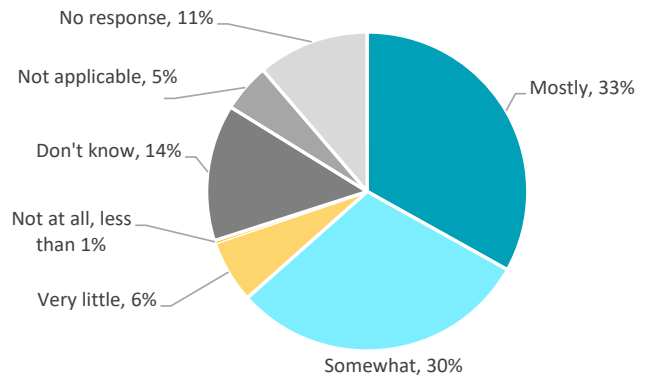
An online survey was used to capture feedback on the CCRC from delegates. Questions related to patient involvement were included on this survey and these results will be used as baseline measures for future conferences. Of note, the response rate to this survey was lower than in past CCRCs (RR=33%) and results may not be an entirely accurate representation of all delegates' views.

Most respondents (63%) indicated that the conference objective related to patient involvement was mostly or somewhat achieved. The presence of PIP participants was noted and appreciated as exemplified by this tweet received by Carrie Shemanko: "As a researcher at the #CCRAconf, it was very interesting and informative to meet the patient advocates. It gave me a different perspective."

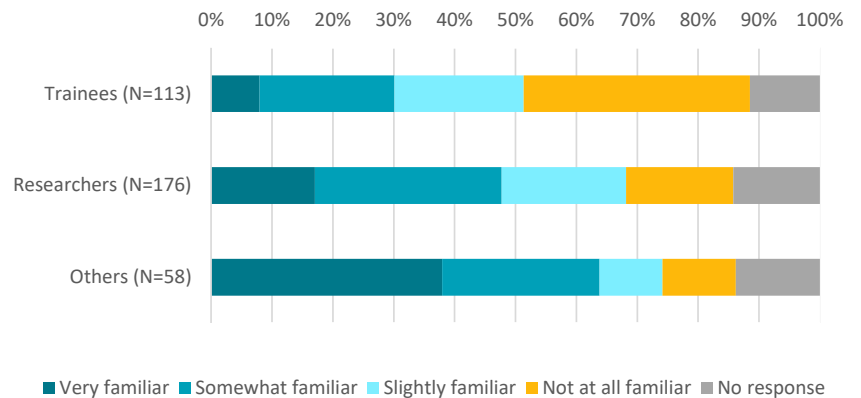
Overall, 45% of respondents indicated that they were very/somewhat familiar with including patients as partners in helping to decide research priorities. This was highest among the "Other" group, which included patient advocates as well as representatives from government organizations and industry. A total of 65% of respondents indicated that they were very/somewhat interested in involving patients as partners in research and this was not different when stratified by respondent group.

Respondents were also asked if they intended to read the patient involvement materials included on the USB that was distributed to delegates. While only 29% of respondents overall indicated that they intended to read the materials, this was positively correlated with interest in patient involvement – i.e., 93% of respondents who reported being very/somewhat interested in involving patients as partners in their research indicated that they intended to read the related materials.

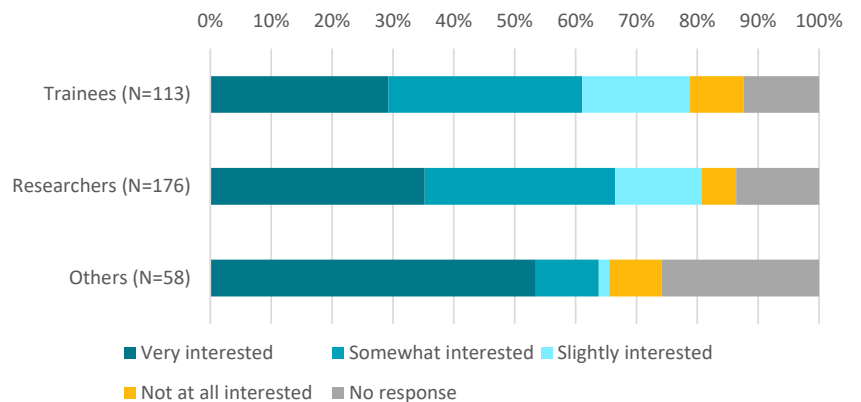
EXTENT OBJECTIVE, "ENHANCE PATIENT INVOLVEMENT IN CANCER RESEARCH IN CANADA," WAS ACHIEVED (N=347)



FAMILIARITY WITH INCLUDING PATIENTS AND/OR CAREGIVERS AS PARTNERS IN RESEARCH TO HELP DECIDE RESEARCH PRIORITIES



INTEREST IN INVOLVING PATIENTS/CAREGIVERS AS PARTNERS IN YOUR RESEARCH



PROPOSED RECOMMENDATIONS

The recommendations below represent a digest of the suggestions provided by participants and mentors and are viewed through the lens of program delivery for the 2019 CCRC.

RECOMMENDATION	DETAILS	RESPONSIBILITY	COST IMPLICATIONS/ CONSIDERATIONS
Change terminology of program roles	Use “patient partners” instead of “patients”; “science partners” instead of mentors to communicate the bidirectional learning process	Executive Office	
Improve the visibility of PIP participants	Continue to use unique lanyards but use larger print to indicate that they are PIP participants	Executive Office	
	Provide (where permissions granted) short patient bios and pictures in the scientific program book and the conference app	Executive Office	Translation; additional pages to program; additional content for app
	Incorporate a patient presentation in the opening session and one plenary session on Day 2 of the conference	SPC + Executive Office	None if recruit from PIP pool
	Ensure 50% of concurrent sessions have patient co-chairs	SPC + Executive Office	None if recruit from PIP pool
	Involve both CCRA Board patient/family representatives on the EPC and in PIP program planning	Executive Office	
	Recruit at least 2 veteran participants on the SPC	SPC + Executive Office	
Improve the poster session experience for patients	Conduct telephone interviews with participants prior to the program to determine their interests so that relevant posters and concurrent sessions can be identified for them prior to the conference	Executive Office	New time commitment
	Implement plain language identifiers for poster categories/identifiers	Executive Office	
	Incorporate a guided tour of curated posters, where the researchers would explain their posters directly to the PIP participants	Science Partners to identify relevant posters + Executive Office (see above)	New time commitment
	Allow patient partners to produce their own posters	SPC mentoring	New time commitment; costs to produce posters
	Develop a patient partners poster session where researchers can interact with patients	SPC	
Augment the PIP handbook	Add the following: Biology 101; genomics 101; proteomics 101; immunotherapies 101; drug pipeline – length of time to develop drugs + regulatory path; drug discovery process – mutations; single-agent therapeutics; chemotherapeutics; immunotherapies. How they fit into drug discovery process.	Executive Office + Science Partners to review	New time commitment
Improve patient-patient networking	Encourage ongoing connections among participants through a closed Facebook	Executive Office	New time commitment

RECOMMENDATION	DETAILS	RESPONSIBILITY	COST IMPLICATIONS/ CONSIDERATIONS
	page or online community. New participants for PIP 2019 could be plugged into this forum early.		
Modify PIP format to facilitate more patient-researcher interaction	Improve integration of the PIP and ECR program	CIHR ICR + Executive Office	
	Re-develop the Saturday curriculum as follows: structured/time-limited introductions, shorter and more focused presentations (30 minutes) with ample time for QnA,	Executive Office	If start Saturday morning, will need to allow for additional food costs
	Implement “Dragon’s Den” where researchers pitch their research ideas/project to a patient panel for input and feedback	SPC + Executive Office (possibly ECR)	
Augment the number of PIP participants	Have 2017 participants mentor/coach new PIP participants in 2019	Executive Office	Costs for PIP coaches; need to determine number of new participants and mentors that can be accommodated with available budget
Augment the number of science partners	Provide smaller patient partner-science partner ratio.	Executive Office	Costs could be defrayed by working with ECR and SPC to identify science partners who are already attending the CCRC
	Identify interested science partners through delegate registration system.	Executive Office	
Increase the number of touchpoints between science partners and patient partners	Utilize breakfasts in addition to lunches to increase opportunities for discussion	Executive Office	
Modify the scientific program to make sessions more accessible to non-scientists	Ask chairs of all plenary and concurrent sessions to prepare and present non-scientific summary slides at both the beginning of the session and at the end which highlight key areas of importance from a patient perspective	SPC + Executive Office	May have difficulty getting cooperation from all chairs
	Ensure that there are concurrent sessions relevant to patient populations (clinical trials, psychosocial/survivorship research, emerging therapeutics)	SPC	
	Schedule two PIP sessions during the concurrent sessions within the scientific program (one on the first day of the CCRC and one on the second day). These sessions will be on major topics of interest and formatted with 30 minutes of presentation and 30 minutes of QnAs. The additional 30 minutes will be used for some informal networking or a group walk.	Executive Office	Will need to ensure the venue can accommodate this additional concurrent

RECOMMENDATION	DETAILS	RESPONSIBILITY	COST IMPLICATIONS/ CONSIDERATIONS
	Have one presentation within a plenary session from a patient-researcher team on the science of patient oriented research	SPC	
Accommodate francophone patients	Translate abstract book, scientific program book, PIP handbook	Executive Office	Major costs – needs to be considered relative to the translation policy for the 2019 Ottawa program
	Offer some simultaneous translation services for 2-3 sessions		

AFTERWORD

Since the program concluded in November 2017, one of the PIP participants, Ms. Ruth Ackerman, has become the new patient/family representative on the CCRA Board, replacing Ms. Diana Ermel. Two PIP participants, Mrs. Roberta Casabon and Ms. Debi Lascelle, have been recruited as patient/family representatives to the newly formed Pan-Canadian Palliative Care Research Collaborative, co-led by Drs. James Downar and Bruno Gagnon. The collaborative represents one of the recommendations from the CCRA's *Pan-Canadian Framework for Palliative and End-of-Life Care Research*. One participant, Roberta Casabon, was involved in a grant application. Most recently, all participants have been encouraged to apply to the Institute Advisory Board call for nominations for the CIHR Institute of Cancer Research.

APPENDIX A. PARTICIPANT PERSPECTIVES

Links

- **Impressions of a Metastatic Breast Cancer patient advocate at the 2017 Canadian Cancer Research Conference in Vancouver**
Heather Douglas – see <http://www.mbcac.ca/impressions-from-2017-canadian-cancer-research-conference.html>
- **Why Does Metastasis Matter? Canadian Cancer Research Conference, Vancouver, November 5-7, 2017**
Nathalie Baudais – see <http://www.mbcac.ca/why-does-metastasis-matter-.html>
- “Greta Hutton the attends the Canadian Cancer Research Conference,” **The Network Pulse**, January 2018 published by the Canadian Cancer Clinical Trials Network
see <https://us12.campaign-archive.com/?u=8d64e9f554805adefabc6db56&id=e6ea6b2e95>

Blogs

The Canadian Cancer Research Conference - Patient Involvement Program (PIP)

Zeba Tayabee (sponsored by the Canadian Partnership Against Cancer and the CIHR ICR)

Being involved with the Equity Advisory Committee with the Canadian Partnership Against Cancer has broadened my horizon and understanding of cancer control and the cancer care system. As a "survivor," I have lived experience which has undoubtedly given me a unique perspective. Given the opportunity to attend the conference helped me ground myself in cancer research and hear about transformative research projects and initiatives that are being undertaken. With over 1000 participants and 600 posters, there was a spectrum of research with different areas of expertise.

As the youngest participant in the PIP program, I felt intimidated yet empowered to share my journey. What I heard in the room from the other 14 participants was amazing. Our stories had one common thread: to share our voices with others and strengthen patient engagement. The introduction laid a foundation for the next few days about what we should expect. It was a packed conference with plenaries, concurrent session, poster presentations, networking dinners and a public lecture. Attending a conference this size for the first time, allowed me to cater it to my own needs and interests - much like a "choose your own adventure" book. There were some sessions that I felt were too scientific and technical, while others were easy to understand. Perhaps a Science 101 would have helped participants like me to develop a basic scientific understanding of the research.

As an AYA cancer survivor who has a higher chance of getting secondary cancers as I get older, learning about new innovative research and cutting edge science was also very important. The work done by researchers and scientists is one of the main reasons, if not the main reason, that I am well and alive. However, knowing what else is available for if and when I need it, has encouraged me to do my own research.

Also, many of the topics that focused on the psychosocial aspects appealed to me. It aligned with my research for my Master of Social Work program, which focused on identity, meaning making and the complexities of survivorship amongst young adults. As discussed in one of the presentations, psychological concerns are one of the biggest unmet needs and we need to be working within healthcare systems to address it. "Whole patient" treatment and care, requires a

"whole system" focus. The importance placed on involving patients within this process can only strengthen this relationship with the research community. Ensuring a patient focus adds a human face to a community often infiltrated with biomedical professionals.

I applaud the CCRA for developing this program so we as patients not only develop our own understanding of research, but also lend our voices and experiences within the cancer care system. The biggest takeaway for me was learning to develop and expand my role as a research advocate and ways in which we can use our stories to advance science. I hope that from this experience, I can learn to use my experience as an AYA cancer survivor to act as an advisor and create my own path of being a young advocate.

Rewarding Experience attending the Canadian Cancer Research Conference (CCRC)

Kathy Brooks (sponsored by the Canadian Partnership Against Cancer and the CIHR ICR)

I feel very fortunate to have been able to experience this conference. The conference was held at the Vancouver Conference Centre on the waterfront and close to our hotel. It was an excellent venue because it allowed easy movement throughout the day to the various presentations and networking opportunities. The CCRC was very well attended with 1086 participants registered, over 600 posters on display, and a very good range of speakers (113 speakers were invited) and topics to choose from. My first impression attending the young researcher's dinner on Friday night is just how young, talented and committed this group is.

Saturday the Patient Involvement Participants (PIP) attended an orientation that gave us

- An overview of the program - we were a pilot project
- Introductions and descriptions of the role of the scientific mentors assigned to our group,
- Cancer Research presentation
- Introductions of the 14 PIP participants and an opportunity to share our stories

There were a number of Plenaries which everyone attended each day but then each individual was able to choose concurrent sessions that they felt were more beneficial to them. That was the hardest part – deciding which sessions to attend. There was variety to choose from and the feedback from the PIP participants was very positive. There were times when the scientific "lingo" was difficult for us but we had opportunities to ask questions and discuss topics with our scientific mentors.

As cancer incidences increase and mortality rates decrease, the reality of the burden of increased costs is very real. "Whole patient care" is now being widely incorporated with a recognition that over 40 percent of cancers in Canada are attributed to modifiable factors. In one of the sessions I attended I learnt that there are exciting advances with very promising results in immunotherapy. Precision medicine is going to complicate cancer care.

It was rewarding to hear in many of the presentations recognition as to how important patient involvement is in research, treatment and follow up care. It was alarming to hear that less than 2 percent of funding is spent on patient support and care. Patients say the cancer journey takes them into a maze. Cancer touches everything. The new cancer journey will be change, challenge and choice. It is important to have relevant information, support and effective communication.

Presentations on genomic testing were eye opening. How much would you want to know about your risk for brain cancer, Alzheimer's, sudden cardiac death, colon cancer, etc.? If you are interested in reading about this topic check out www.genomicsadvisor.com. Costs for genomic testing have decreased but are still not inexpensive.

There were opportunities throughout the conference to view the posters and exhibits. The researchers were there to answer questions and explain their research. I come away feeling very confident in the future of cancer research because of the innovation and breadth of topics covered.

- One scientist who lives in Nova Scotia where there is an abundance of apple peels being wasted has found that he can use apple flavonoids to selectively kill and suppress the proliferation of triple negative human breast cancer cells.
- Another researcher has created a handheld diffuse optical breast cancer imaging probe that can be used for detecting breast cancer tissue.
- A protein that can be given to cancer patients to prevent reoccurrence.

With over 600 posters you can imagine it was impossible to see and understand them all, you needed to pick and choose ones that particularly interested you personally. The four days were packed with information and we all came home tired but I am motivated to learn more, volunteer more, and try and give back more.

2017 PIP SUPPORTERS

