



2018 PAN Conference Evaluation Report

The Patient/Caregiver Partner Perspective

Annette McKinnon
Carolyn Canfield
Donna Rubenstein
Kerri MacKay
Kathy Smith
Amy Ma

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About PAN

The Patient Advisors Network (PAN) - Réseau des patients partenaires (RPP)

We are a community of people who have received health services or cared for those who have, and we are committed to improving healthcare as advisors for the good of all across Canada. Together, we can create a greater collective impact.

We do NOT advise patients about care.

Patient Advisors Network was incorporated April 1, 2016, as a Canadian not-for-profit group. Our operations depend on private donations from among our members, while we seek sustaining funding from people and organizations that support our objectives.

Objectives

The Patient Advisors Network is a community of practice for patient and caregiver advisors that acts:

- to provide advisors and partners in healthcare a safe space to get to know and learn from each other.
- to build our capacity to be better and more effective at what we have chosen to do.
- to attract and support newcomers to the work.
- to have a greater collective impact on healthcare by coming together as a group for our own and other projects.
- to provide our understanding of various effective ways to collaborate
- to provide our experienced insights into all aspects of the healthcare system

The demand for effective patient partners and advisors is growing exponentially, while recruitment may lack adequate orientation, training, and support to prepare incoming patient partners. Learning from fellow members and mentoring each other can help to close the gap.

The patient and caregiver voice needs to be heard not just as lone individuals but as a tapestry of different experiences centering on a common goal of improving healthcare for all. PAN provides a locus for this presence.

Acknowledgement

We would like to acknowledge our survey respondents for filling out the survey. We appreciate the serious reflection and commitment so evident in their submissions.



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Overview

What are Patient Advisors?

The **Patient Advisors Network (PAN)** is a community of patients and family caregivers across Canada whose members are committed to improving healthcare for the good of all. PAN is independent of healthcare institutions or sectors, commercial interests and political affiliations.

Patient advisors collaborate, co-create, and partner with healthcare providers, researchers, administrators, and policy makers in order to share patient and family experiences and to ensure that applying the wisdom gained from the lived experience of patients and families becomes the norm for all aspects of healthcare.

Throughout this report we will be using the term “patient partner” to designate patient and family advisors, as well as caregiver advisors.

Background

Patient partners are relatively recent arrivals as attendees at healthcare conferences. Organizers and sponsors are often unfamiliar with our unique circumstances and constraints. The lack of shared experience on both sides can create mismatched expectations that may lead to disappointment and upset.

Patient partners lack access to the usual platforms for distributing conference information. They are unlikely to hear about conferences through calls for speakers, abstracts and registration through professional organizations and networks. Reminders about participation miss patient partners as they travel through networks of professional colleagues and listings in professional publications. Patient partners are much more likely to hear about conferences through personal connections and social media.

Patient partners who wish to participate in conferences don’t often benefit from financial support. They don’t qualify for educational or professional development credits, and their careers are not furthered by attending or speaking at conferences in the usual sense. Conferences do, however, offer a powerful route to building capacity that is equally beneficial to professionals and partners. Patient partners also wish to network and collaborate, share their experiences, and expand their understanding of the healthcare system so that they can contribute to their greater potential as a partner in improving care.

Purpose

The first annual Conference Evaluation Survey was undertaken by PAN in 2018 to learn about the experience of Canadian patients and caregivers at conferences. The survey provides perspectives on the state of patient inclusion in conferences and the value gained by patients from their conference experiences. The survey responses highlight how patient participation in conferences strengthens their subsequent patient engagement contribution. Greater recognition of this underused opportunity would benefit patient partners and the medical, technical, and scientific sponsors for overall healthcare system advantage.

This first survey provides a baseline for what we have learned and can apply in coming years. Administering a recurring survey will enable PAN to monitor changes, identify innovations and provide



insight into the effectiveness of evolving patient Inclusion practices. Readers are invited to offer suggestions for improving future surveys and reporting their experiences through the PAN website.

Audience

This report is intended for both patient partners and those who plan and organize healthcare practice, policy, and research conferences.

For patient partners, the information in this report can guide their decisions whether and where to invest their time, energy and expertise in attending conferences. They can assess which features of conferences will provide them with the learning and networking that best builds their capacity as patient partners. They can gain understanding of what is needed for them to contribute productively as participants, speakers, panelists. Findings of this survey are intended to spark conversations between advisors and organizers to work together to improve the contribution patients and caregivers can provide at conferences.

Report findings offer organizers specific suggestions around planning for patient inclusion at their event. These insights should assist organizers to include patient perspectives, as well as meet their unique needs as conference attendees. We hope the report will also lead to a more robust and effective relationship with planners and patient partner as co-creators of conferences in the future.

Methods

PAN members designed the survey and wrote the questions. Through PAN's Community Discussion Board and other social media networks, members and other patients and caregivers were encouraged to complete the Conference Evaluation Survey after each conference they attended. The survey was hosted on Survey Monkey and accessible from the PAN public site, as well as promoted via PAN message boards. Members shared the Survey link on social media, often via Twitter, using the hashtag of the conferences they attended. Through the calendar year 2018, 74 surveys were received.

Respondents were asked to answer a mix of multiple choice, rating, and free text open-ended questions.

The 35 questions addressed:

- name and location of the conference;
- ease of discovery of conference details;
- financial assistance and related issues;
- welcome and consideration of patient/caregiver status;
- roles at the conference;
- conference logistics and amenities;
- co-design of conference;
- quality and value of the experience; and
- potential improvements for the future.

A complete list of the conferences attended by respondents can be found in Appendix A; a complete list of survey questions are in Appendix B.



Key Findings – Summary

- Conferences vary widely on how well they include and support patient partners.
- Patients and caregivers see conferences as a welcome opportunity for learning, sharing and making new connections, just as professional health workers and researchers do.
- Financial support, similar to support given to healthcare attendees would improve diversity and representation by lowering economic barriers for the broader patient and caregiver community.
- Conference experiences ranged widely in terms of reported ability to participate effectively, barriers to attendance, and access to sessions.
- Sharing best practices to support patients and caregivers could improve future experiences and enhance effective patient and caregiver contributions to conferences.



A Look at the Survey Responses

Qualitative/Open-Ended questions

THEMES

Responses expressed four general themes:

LEARNING

Attendees strongly value their new learning, seeing this as developing their effectiveness as patient partners in health and research initiatives. Patient partners are voracious learners, who strongly appreciate their exposure to a broader community of people with expertise in essential areas. Patient partners weave these connections and collaborations into a larger, more engaged, effective and productive partner role.

NETWORKING

Networking and collaborating were highlighted as strengthening patient partners' connections and credibility across all system and professional silos, and opening doors to future partnerships and collaborations.

INCLUSION

Patient partners strongly valued formal inclusion of the patient voice in conferences to bring new and authentic insights to other participants and to the health system. They want to see more authentic and diverse engagement and more patient involvement in planning conferences. Another issue that arose was the desire for greater transparency around patient-related processes, for example, in selection for registration, scholarships, and recognition awards.

INSIGHTS

Patient partners suggested transformative changes that they would welcome, such as routinely considering patients and caregivers as active members of their conference audience. Anticipating their participation as essential to conference success would require more planning and co-design in advance with experienced and diverse patient partners. Creating more opportunity for patient partners to attend would broaden their ability to work more effectively for health system change.

TOKENISM WAS A CONCERN

Parent partners are very sensitive to perceptions of being 'co-opted'; included in conferences 'for show'; being segregated from or dismissed by other attendees; and being 'controlled and managed' when they attend.



Survey respondents communicated that the patient voice is an essential part of every aspect of healthcare.

"We are, or should be, present to influence priorities; to offer insight into changing expectations; to signal emerging trends in use of clinician time and availability; and to carry this knowledge into the population." *

"Patients, community members, practitioners, policy people and researchers meet on equal footing."

LEARNING – KEY BENEFIT

Learning was the benefit most frequently mentioned, with the highest value topics being innovation, new knowledge, Pan-Canadian practice and challenges, and scientific findings. The benefits of networking elicited comments about the value of having an opportunity to be a part of conversations that could broaden or change the perspectives of health influencers, as well as the crucial importance of connecting and networking with other patients.

THE VALUE OF PATIENTS

The contribution of patients adding value to conferences was mentioned second most frequently. Patient partners appreciate the respect paid to our understanding of the system. Feeling included, as "being treated like a true partner" matters.

"They need to strongly consider for the future what the true value is of having patients. It has to be more than just saying we are there."

POWER IMBALANCE

There were a number of comments that touched on the power imbalance.

"We need more people recognizing the hypocrisy of talking about 'valuing patient partners' and not translating that into \$\$ to support their participation"

"Very little recognition that patients are actually PARTNERS throughout the life cycle of research from priority setting to implementation. Instead it often sounded like we are easily ignored artifacts generated by SPOR funded projects."

PATIENT PARTNERS

Patient partners expressed optimism about their acceptance at more conferences than in the past and experienced more positive responses from conference organizers and professional attendees.

"I am optimistic that all attending took away a powerful understanding that empowering patients as partners in improvement projects will result in far more profound impacts than are otherwise possible."

"Everyone had a voice that was given time and respect."

"Patients in attendance were regarded with genuine appreciation and gratitude. Physician leaders seemed humbled by their experience in partnering with patients and gaining insight into their selfless generosity, curiosity and commitment as team members. This enthusiasm



was a powerful influence on those physicians who had not yet taken the step of inviting patients into their improvement initiatives".

"Organizers took risks in opening opportunities for patient partners to speak freely about their roles in collaboration for improvement projects. The strategy paid off in an event that truly showcased the importance of involving patients and caregivers in improvement initiatives, from the start. The organizers also took pains to invite top health provider executives along with the improvement and professional organizations in the province."

"The organizers really showed that they wanted to learn and were willing to put action and money to make patients and family carers comfortable, productive and appreciated. This is so rare!!"

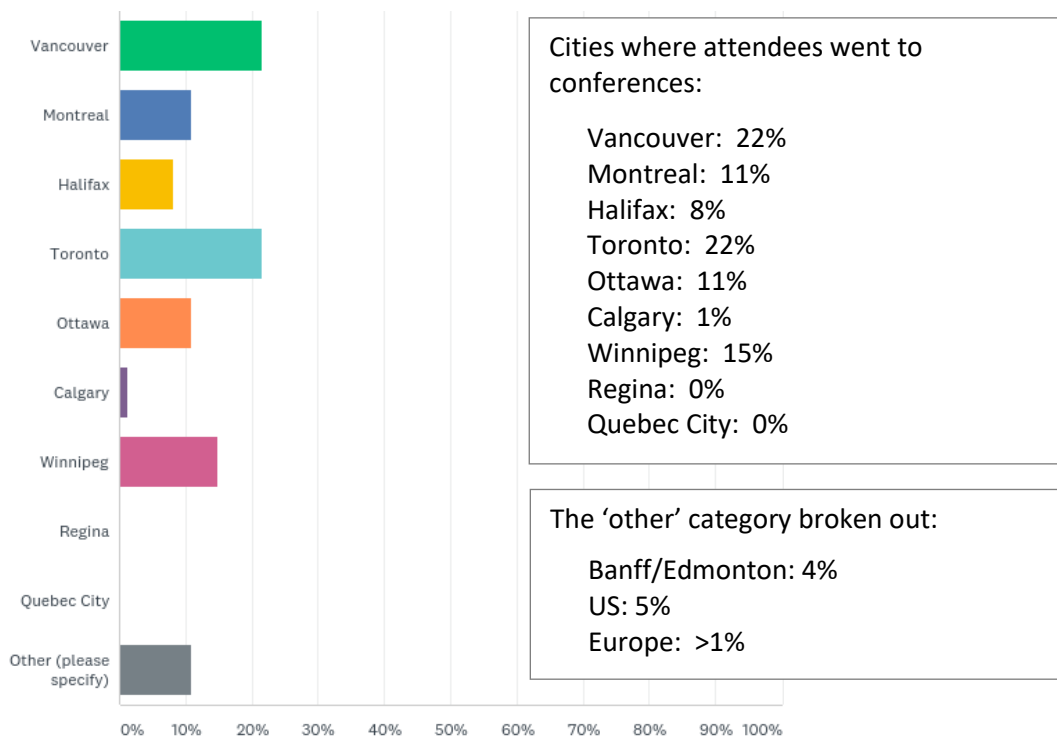
BENEFITS TO HEALTHCARE SYSTEMS AND RESEARCH

Patient partners see benefit to healthcare and research through their participation:

Expanding conference involvement today will extend a benefit in future years as we embed capable patient partners for a public contribution in planning, policy and accountability with health professionals.

The Quantitative Questions

IN WHAT CITY DID THE CONFERENCE TAKE PLACE ? Q 1



Respondents attended conferences across the country with Toronto and Vancouver the most frequent locations at almost 22% each. Patient partners living in these larger cities may find it easier to attend locally because the transportation and accommodation costs are minimal. Since the competition for subsidies and scholarships is intense many are unable to attend conferences away from their home area.

The fact that Winnipeg ranks 3rd at 15% reflects the efforts of just one conference, the CMA Summit, which recognized patient partners as essential members of their audience and supported a large number to attend.

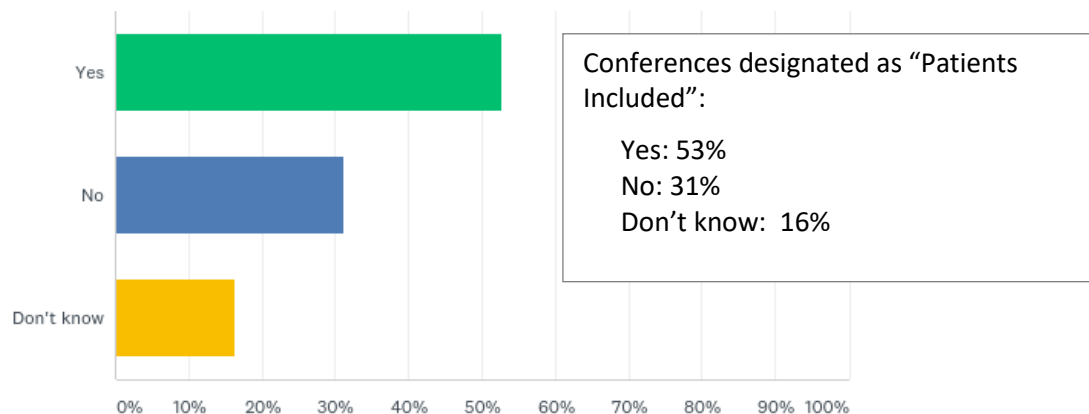
Interestingly 6% of responses applied to international locations.

WHICH CONFERENCE DID YOU ATTEND? Q2

The 35 different conferences that Patient Partners attended crossed into many facets of healthcare: disease interest groups, quality improvement, patient engagement, digital health, health policy, health human resources, research funding groups, and research networks were all represented.

Of the 74 responses received, the CMA Health Summit was the most frequent event of our survey. This was likely due to their initiative to ensure a large number of patient partners were financially supported to attend and also their link to the survey in the conference follow up messages. We would be delighted if more conferences adopted this practice. (*Appendix A provides a list of conferences attended by patient partners*)

WAS THE CONFERENCE DESIGNATED AS “PATIENTS INCLUDED”? Q3



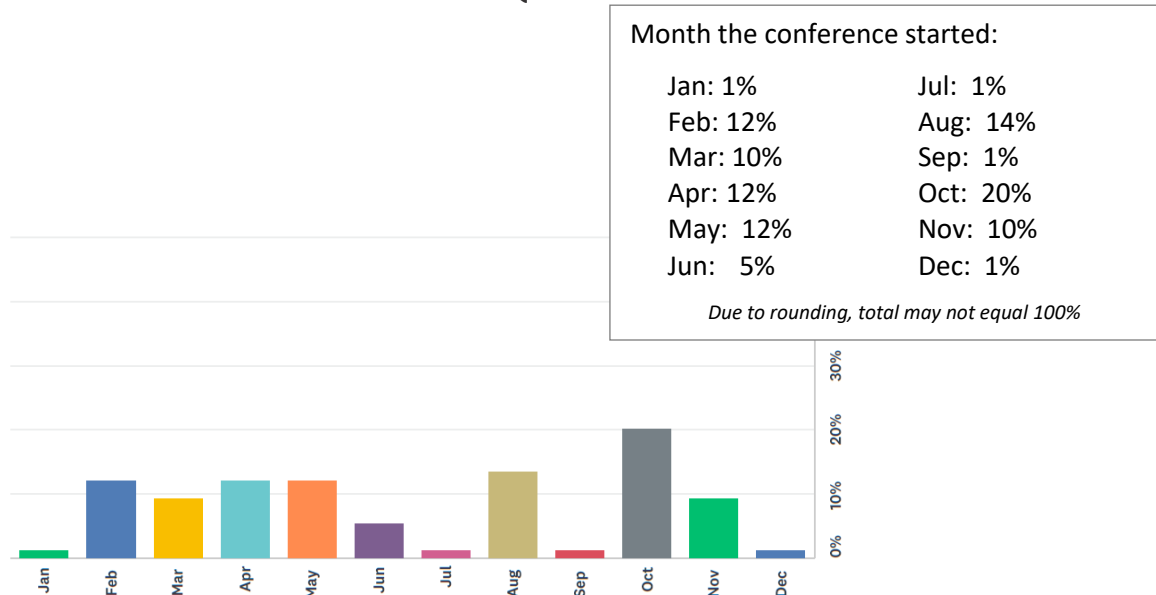
Respondents identified 53% of the conferences as ‘Patients Included’, 31% were not ‘Patients Included’ and 16% of respondents did not know the conference status. In fact some responses stating that the conference was not ‘Patients Included’ were for conferences that indeed had this designation. When corrected there were actually 65% of the conferences with a “Patients Included” designation.

The “Patients Included” designation is typically featured in all publicity including social media like Twitter and is a means of highlighting the status to patient partners. The survey numbers suggest a lack of awareness and room for more education and communication about this self-assessed designation.

<https://patientsincluded.org/>

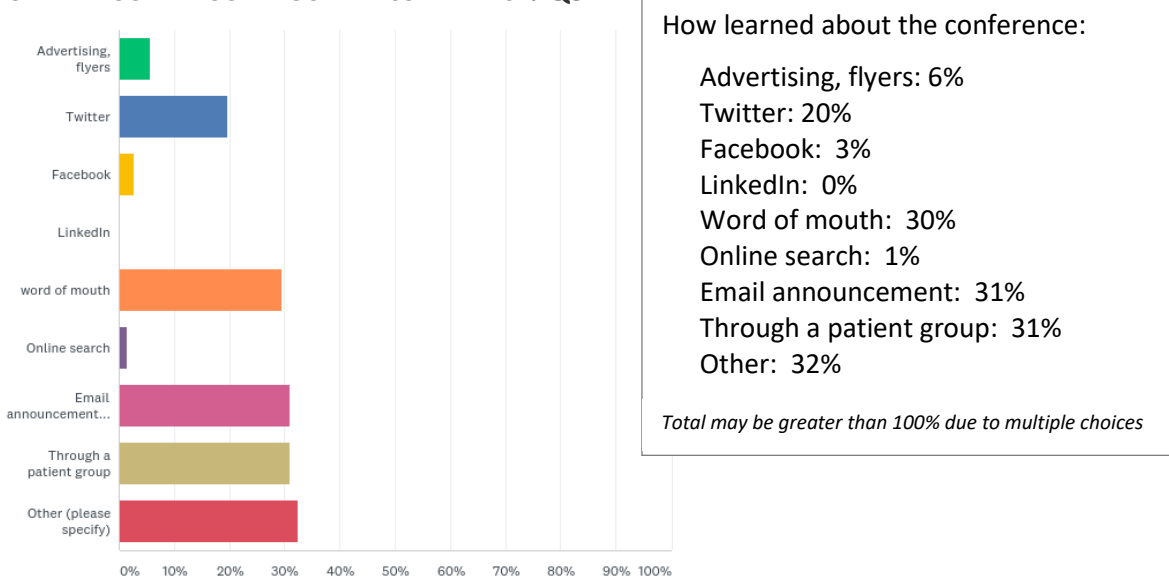


IN WHAT MONTH DID THE CONFERENCE START? Q4



The most popular months for events were February to May, and August, October, November. Overall October was the leader with over 20% of conference respondents.

HOW DID YOU FIND OUT ABOUT THE CONFERENCE? Q5



Many patients learned about conferences through their own networks and not from the sponsoring organizations. Email, Twitter and word of mouth were the most common choices, mentioned in 30% of the surveys.

11% learned about the conference through invitations to speak or present showing a demand by organizers for patients to participate in a visible way, sometimes as a 'token patient' on the program.



The results suggest conferences are not actively targeting patients as participants. Conference organizers and sponsoring organizations could improve conference promotion and awareness beyond traditional methods to reach eager learners among patient and caregiver partners.

Comments Heard in 'Other' Category:

"Physician forwarded me her email about conference + CMA patient voice program"

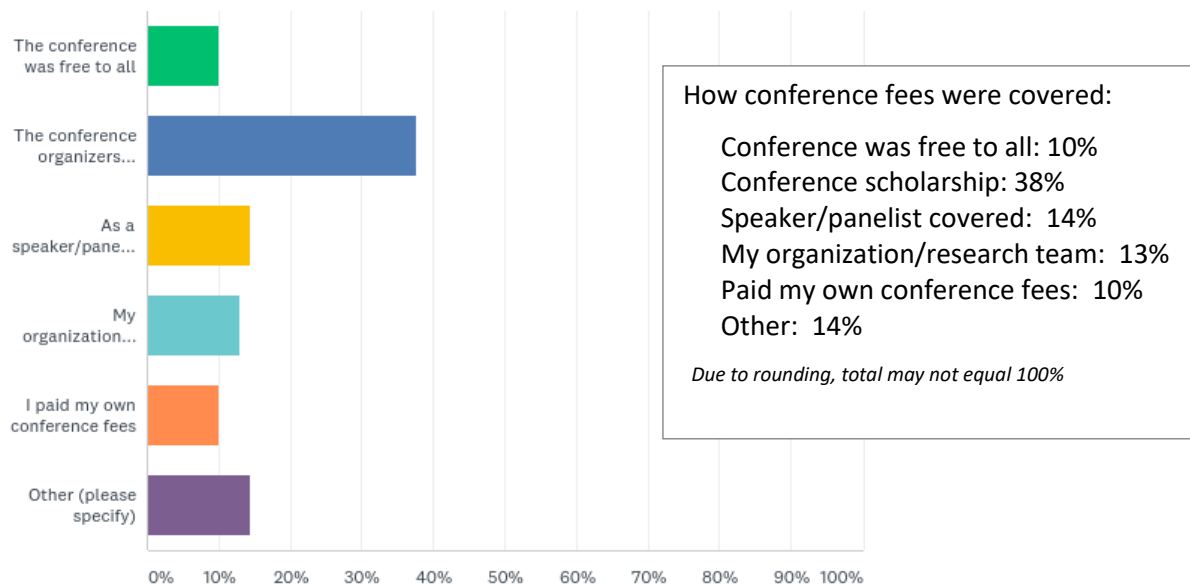
"Invited as a citizen advisor with CFN"

"I was watching out for it because I went to HQT last year"

WAS IT LIVESTREAMED? Q6

Over 40% of the respondents said that their conference included at least some livestreaming components. This is also encouraged by the Patients Included guidelines. The current survey did not ask about the value or experience of livestreaming and warrants reaching out to the broader patient partner community. This is a potential mechanism to increase participation and we may probe further in future surveys and/or discussion forums.

HOW WERE YOUR CONFERENCE FEES COVERED? Q7



Looking at how the fees for the conference were covered, almost 60% of respondents received a scholarship or did not need to pay since they were presenting. Another 27% had their fees covered by their research team, patient association or as citizen advisors. 13% paid their own way. Conference fees are a serious barrier, even for local patient partners. Without a scholarship or subsidy, financial outlays incurred by patient partners ranged from free when sponsored to as high as \$3,000.

The large numbers of applications for patient scholarships to conferences that organizers report receiving reflects the keen interest that those who completed our survey demonstrated in their answers.



"I lobbied long and hard with clumsy success that one of the sponsoring organizations was essentially shamed into waiving my registration. Sadly, I don't believe it set a precedent."

"I paid a special patient rate; free was mentioned, but I have a part-time job & wanted to pay something to help offset costs for other patients to attend."

HOW WERE EXTRA EVENTS COVERED? Q8

Patient partners indicated limited communication about extra events beyond the core conference schedule. They were more difficult to access when events had costs over and above the conference attendance fee. In 25% of responses there were no extra events or they were free for everyone. In almost 45% of cases these fees were covered for speakers, or by scholarships, with other organizations or research teams paying for 5% of patients and caregivers.

10% of patient partners paid from their own pocket and 20% did not attend. As the number of patient partners increase, conference organizers need to explore ways to support their participation at extra events.

"There was a lunch I didn't know about until I got an email saying that it was full."

"I didn't attend pre-conference sessions because I couldn't afford the fees".

"I didn't want to attend any extra events; just the conference was exhausting!"

"The social event was pricey, even with a scholarship"

HOW WERE YOUR TRAVEL AND ACCOMMODATION EXPENSES COVERED? Q 9

Nearly half of the respondents had their travel, accommodation and expenses paid by the organizers, while another 17% were supported by patient groups and organizations, and research teams.

Almost 17% paid their own way, while an equal number had no expenses. Patient partners do their best to find ways to minimize costs in their quest to learn more and network. If cost barriers are removed, conferences will see a more diverse and larger group of patient partners participate.

"It was in my home city so minimal cost. I did have to take my own lunch or pay extra to organize lunch myself."

"A travel bursary was provided. I took care of my own expenses. Reimbursed later. Also, I stayed with family."

PLEASE COMMENT ON ANY ISSUES YOU HAD WITH THE COSTS OF ATTENDING THE CONFERENCE Q10

This was an optional question.

The comments showed an agreement that financial barriers are a significant issue and many of the respondents made personal arrangements for accommodation to attend.

The responses revealed a range of experiences. At some conferences those who answered stated that there were no financial issues that impacted them, or they complimented the conference organizers' for supporting patient partners. Such actions reflect best practices for other conferences. For example:



"Organizers made their travel policy available well in advance, offered to make reservations for me to avoid me paying costs up front, and forwarded the partially completed expense claim promptly after the event. Communication was always helpful with a quick turnaround."

"As a presenter I was delighted to receive a fair honorarium."

"My airfare reimbursement came through before I left for Winnipeg!"

Those who had difficulties with cost issues commonly mentioned slow or delayed reimbursement, leading to "financial hangover" which can go on for months.

"Paying first and being reimbursed later is a challenge for individuals...especially seniors...if you show up to fly or stay it should be covered at source."

"The costs are prohibitive and exclusionary to the premier national conference for research in health services and policy. Even with juried acceptance of our abstract!"

And some insight into where the 'unheard voices' are:

"Personally, I am on disability, which is barely enough to live on. Attending conferences would be impossible for me without full funding, preferably by the organisation paying the fees in my name and a per diem paid in advance, too, or available to be picked up at the conference."

Note: The survey covers patient partners who did attend conferences. We have no data from patients or caregivers who are unable to attend conferences as they are busy at work, must balance holiday time and sick time in order to stay employed, or otherwise cannot absorb the financial costs to attend.

Other financial issues:

"I have to impose on friends or my husband to get to the conference. Mileage is not covered for any of those involved."

"I was told the special conference fee was sold out for some of the nights. It's expensive to eat when you are staying in the high priced part of town."

"My daughter spoke (presented) with me and my family had to cover her travel costs."

"I paid for my poster and handout printing costs without assistance."

"I had to renew my passport, and just managed it with the amount of notice given. Extra expenses include airfare, health insurance, roaming charges, meals."

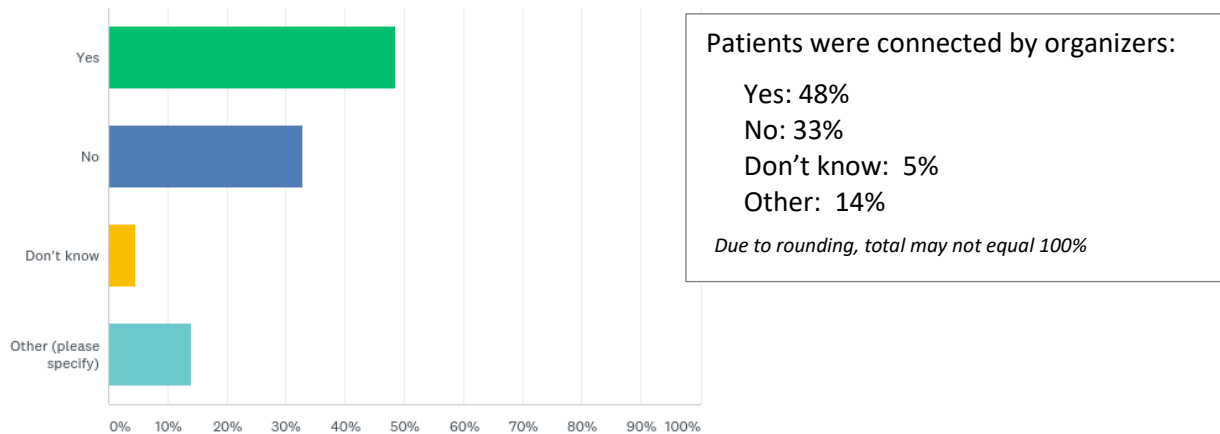
DID YOU AS A PATIENT, CAREGIVER OR MEMBER OF THE PUBLIC FEEL WELCOME AT THE CONFERENCE? Q11

47% of respondents felt very welcome and gave top marks to conferences. Another 25% were positive, but a little less, only 3 respondents felt unwelcome.

This area could be improved. Once organizations go to the trouble of making sure that patients are part of the audience, it's disappointing when the actual event does not match their good intentions in the eyes of the patients and caregivers.



**DID THE ORGANIZERS CONNECT PATIENTS AND CAREGIVERS WITH EACH OTHER AT THE START OF THE CONFERENCE?
FOR EXAMPLE, A MEAL, A SPECIFIC GATHERING PLACE FOR PATIENTS AND CAREGIVERS, PREVIOUSLY BY EMAIL Q12**



Less than half of conferences represented in this survey connected patient partners in advance or during the event. This is a significant lost opportunity for strengthening patient capacity and a priority area for improvement.

"I asked for the organizers to make an announcement so that we could meet at the end of day one to at least say hi to one another"

"Patient Registration was segregated from other conference participants and time to connect with other patients was very limited"

"Patients were able to post a meet-up notice on the conference app. The organizers did nothing to connect patients."

WERE THERE OTHER PATIENTS, CAREGIVERS OR PUBLIC ATTENDEES AT THE CONFERENCE? Q13

84% said there were other patients or public attendees though 9% did not know if there were others.

"Yes, but it was impossible for me to know how many."

"Not applicable. I was the only patient, invited as a speaker"

DURING THE SESSIONS, DID YOU FEEL COMFORTABLE EXPRESSING YOUR OPINION, OR ASKING QUESTIONS? Q14

30% did not feel comfortable expressing their opinion or asking questions. Conference organizers would benefit from examining barriers and solutions to help patient partners feel more comfortable participating.

WERE PATIENTS INCLUDED AS SPEAKERS OR PANELISTS WITHIN CONFERENCE SESSIONS? Q15

25% said there was no patient partner as a speaker or panelist or did not know if there was a patient speaker or panelist.



"Some sessions had a patient presenting, most did not."

"I believe only 1 patient was on a panel and 1 patient a guest speaker"

**DID YOU FEEL THE PRESENTATIONS WERE OF INTEREST FOR PATIENTS, CAREGIVERS AND MEMBERS OF THE PUBLIC?
Q16**

76% said "yes". Three in four respondents found the presentations of interest to patient partners. However, some patient partners were evidently content to attend even though they may have been faced with a steep learning curve.

DID YOU HAVE OPPORTUNITIES FOR NETWORKING WITH HEALTHCARE PROFESSIONALS/ RESEARCHERS/ POLICY MAKERS? (WHETHER YOU TOOK ADVANTAGE OR NOT) Q17

74% indicated there were opportunities for networking with healthcare professionals/researchers/policy makers. This is another opportunity for conference organizers to improve support for patient partners. This might include providing information about participants in advance to facilitate planning for a person to person connection, setting up dedicated spaces and times for networking, and assigned seating to ensure there is a mix of attendee backgrounds at each table.

WERE THERE OPPORTUNITIES FOR NETWORKING WITH FELLOW PATIENTS, CAREGIVERS AND MEMBERS OF THE PUBLIC? (WHETHER YOU TOOK ADVANTAGE OR NOT) Q18

45% of responses were neutral or negative regarding opportunities for networking with fellow patients, caregivers and members of the public. These answers correspond to question 12 where 50% of organizers/hosts helped patient partners to connect. Again, conference organizers would benefit from examining ways to help patient partners connect and ultimately feel more comfortable participating. This might include providing a forum for connecting patient partners in advance of the conference and specific activities or dedicated space for meeting during the conference.

WAS THE VENUE, INCLUDING WASHROOMS, ACCESSIBLE FOR THOSE WITH MOBILITY ISSUES? Q19

Of the respondents, 76% said "yes", 8% "no" and 16% said "don't know."

"The hotel was pretty isolated, so it was a long way to restaurants except for the one at the hotel."

"Navigating from the hotel to the conference centre by foot was complicated and unclear."

"There was a shuttle to/from conference site available; school bus used would not have been wheelchair accessible for those needing accessible transport."

"Hotel parking 100% NOT accessible-struggled with stairs up/down to elevator-worst I ever encountered!"

WAS ARRIVAL TO THE VENUE EASY FOR YOU (BY CAR, BY PUBLIC TRANSPORTATION, BY MOBILITY ASSISTED TRANSPORT, OTHER)? Q20

Of the respondents, 76% said "yes", 8% "no" and 16% said "don't know." Any conference with access challenges introduces an unacceptable barrier to participation that limits representation from the



patient partner community. Access for those with mobility issues should be mandatory and verified by conference organizers when selecting a venue. A walk through with accessibility in mind would prevent issues during the conference.

In comments, patient partners appreciated easy access from hotel to conference centre, since walking long distances from one area or event to another caused problems for patient partners with mobility issues, direction finding problems, and those who are easily fatigued. This also allowed easy return to rooms for rest breaks.

"The layout was difficult requiring more than one elevator (widely separated) to travel several storeys and considerable distance from one end of the hotel to the other. This was not suitable for mobility impaired or slower moving participants."

Access to parking, elevators, transit, and even entry to parts of the buildings was another issue.

"Some elevators are obstructed by glass doors to access, posing a challenge to accessibility depending on arm/hand strength/grip or those using mobility aids."

"The venue was massive and there was limited seating in the main hall. Many people were standing."

WERE YOU ASKED FOR FOOD REQUIREMENTS AND RESTRICTIONS BEFOREHAND? Q21

Only 67% of respondents indicated that the conference asked about this. This logistical oversight is a serious health concern and impacts patient partners as well as other participants, detracting from the health orientation of a conference. Most facilities are able to accommodate dietary restrictions, so conference planners need to ensure their registration includes this question.

Lunch time issues and food preferences showed up as problems. For example, the weight of the plates commonly used in hotels created problems for some when they needed to be carried a distance to the eating area or room.

"The distance between the food service and tables for eating together as patients was difficult for anyone with any sort of mobility aid and some of us without!"

"Very noisy, no place to sit to eat lunch, juggled on plates. Very crowded access to refreshment breaks."

"We weren't asked and some people found nothing they were able to eat at some meals"

SCHEDULE SENSITIVE TO ANY SENSORY DISABILITIES AND/OR FATIGUE Q22

50% of respondents said that the conferences were sensitive to this, revealing a major area of opportunity to improve the patient partner experience to support full participation. Building in more refreshment breaks could reduce the fatigue barrier and introduce greater networking opportunities.

"Some conferences we have been to have loud music played between speakers and at breaks, making conversations very difficult."



WERE QUIET REST AREAS AVAILABLE TO THOSE WHO NEEDED THEM? Q23

Half of the respondents indicated that a quiet rest area was provided at the conference. This quote embodies the ideal: "Hotel had lots of alternative and quiet meeting areas." This is a key observation about the ideal conference venue layout and proximity to the patient accommodation. Most patient partners attending conferences are dealing with active health problems and appreciate this consideration.

Often though this was the experience:

"Yes, there were empty meeting rooms, but nowhere to really rest. The schedule was so tightly scheduled, it was hard to actually rest. The distance to the hotel made it difficult to take a "recuperation nap".

"There were limited areas elsewhere in the hotel with less visual congestion, but no escape from noise"

OPTIONAL COMMENTS ABOUT ACCESSIBILITY Q24

These comments are included in preceding questions.

WERE PATIENTS/CAREGIVERS INVOLVED IN CO-DESIGNING THE CONFERENCE? Q25

27% said "yes." While the percentage is low, respondents may not be fully aware of how conference planning was handled and the result may not be reflective of actual patient participation.

DID PATIENTS/CAREGIVERS PARTICIPATE IN THE SELECTION OF THE SPEAKERS AND PRESENTATIONS? Q26

20% said "yes." Again the percentage is low; however respondents may not be fully aware of how conference planning was handled and the result not reflective of actual participation.

Greater communication around the involvement of patients in conference planning is an opportunity for conference planners to enhance patient inclusion. Many patient advisors are interested in the planning stages.

WOULD YOU RECOMMEND THAT PATIENTS, CAREGIVERS AND THE PUBLIC ATTEND THIS CONFERENCE NEXT YEAR? Q27

Two out of three respondents would recommend the conference they attended to patients, caregivers, and the public. The comments from some of those who chose "Other" were particularly illuminating.

"Patients need to attend this conference for our own capacity development, networking and contribution, just like professional attendees. Otherwise, the present financial barrier and exclusionary program make a mockery of provincial patient engagement efforts and the national Strategy for Patient Oriented Research."

"Think applicability of this conference to patients is very dependent on their interests. Most sessions were not completely accessible to 'general audiences' and many were quite



technical. (An irony given workshops on "plain language" and "clear communication" were available, exploring with attendees how to minimize jargon!)

"This is an event by physicians and to date only involving physicians, policy researchers and senior government decision makers. However, their experience with me as a solo patient leader had the impact of an invitation to join the working group! I think they discovered the value of an informed and articulate citizen-patient."



Conclusion

The strong response to this first ever PAN survey to evaluate healthcare conferences from a patient perspective reflects a high value placed on conference attendance and great enthusiasm for helping to improve the experience.

Overall the survey responses describe positive and rewarding experiences, and also highlight key areas for improvement to meet patient partner interests and needs. These are still early days in healthcare partnership and there is much to be learned on both sides.

We hope this feedback will have value for conference organizers who wish to expand their attendance to welcome this rapidly growing constituency of co-designers and co-producers of healthcare. We recognize that as patients and caregivers, we currently make up a small percentage of conference-goers.

"Patients were treated with respect by professionals, as equal (and perhaps even MORE valuable) participants by being offered generous time and full attention to the issues raised and insight offered."

While the PAN survey respondents are only a small sample of the overall patient and caregiver advisor community, these insights will serve to expand access and support for greater diversity.

On the patient partner side, we need to anticipate and prepare for what to expect and how to benefit most effectively from our investment of time and energy to connect, to network and to learn. Conferences are a key

resource for building patient partner capacity. Better capacity will strengthen every engagement we are involved in.

We can all learn from the barriers and benefits highlighted in this report. For example: Improved financial support would open access to greater diversity among patients and caregivers in attendance. Without assistance patient partners who lack financial ability, especially those who live in rural and remote areas of the country, will continue to remain unseen and unheard.

The opportunities that patient partners most valued at conferences were networking, connecting and learning. Putting these new skills, resources, and knowledge to work cultivates more effective partners and valued team members. There is no doubt that patients and caregivers return great benefit as well to the attending professionals in this rich knowledge exchange of ideas and experience.

"Excellent networking with fellow patient advisors. Warm reception for the patient voice by organizers and attendees. Excellent facilitated and informal preparation and reactive discussion for all the invited patient advisors. Organizers very open to learning that "representative" is not appropriate for the patients in attendance.

Patients seem to have been included as an afterthought, but tremendous effort and expense was devoted to making it happen in as ideal a fashion as they could conceive. Kudos to this conference! The organizers were adaptable and generous."



Throughout the survey, respondents expressed eagerness to build their knowledge and networks to become more effective team members. They want to see more authentic and diverse engagement, including more patient involvement in planning conferences. By reducing the barriers of cost and travel logistics, larger numbers of patients could attend to reduce a sense of tokenism and to broaden the spread of involvement for change.

Increasing the population of knowledgeable and well-connected patient and caregivers helps increase the supply of capable partners ready to join the councils, steering committees and research projects. It is in these countless activities and roles where healthcare professionals are discovering that the unique voices of system users are essential to co-creating better health outcomes and experiences for patients, families, practitioners and communities.

For Conference tip sheets, visit our site www.patientadvisors.ca.

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*Quotes throughout the report are from the survey respondents.



Appendix A: Conferences

NUMBER OF RESPONDERS	CONFERENCE
11	CMA Health Summit 2018
5	HQT- Health Quality Transformation hosted by Health Quality Ontario - Fall2018
5	CADTH Symposium- Canadian Agency for Drugs and Technologies in Health - April 2018
5	Quality Forum 2018 - BC Patient Safety and Quality Council - Feb 2018
4	CAHSPR- Canadian Association for Health Services and Policy Research -May 2018
4	SPOR Summit
3	Canadian Health Workforce Conference
3	Choosing Wisely Canada National Meeting
3	Canadian Pain Society Scientific Meeting
2	eHealth 2018 - Canada's National Conference and Tradeshow - May 2018 Annual National Forum on Patient Experience - Fall 2018
2	Canada Health Infoway Partnership Conference - Nov 2018
2	CRA Canadian Rheumatology Association Annual Scientific Meeting
2	HIMSS 18
2	CRA/AHPA
1	Annual National Forum on Patient Experience - Fall 2018
1	IDEAS QIPSF
1	Human Resources for Health Dialogue-National Specialty Societies, Royal College of Physicians and Surgeons of Canada
1	HF Update 2018
1	Canadian Frailty Network Conference
1	Infection prevention and Control
1	Specialty Services Committee- Physician Quality Improvement Summit (SSC-PQI)
1	American Academy of CP and Developmental Medicine
1	Canadian Cardiovascular Congress



1	#WSC18-World Stroke Congress
1	IPCC
1	EULAR- European League against Rheumatism
1	BC Rural Health Research Symposium 2018
1	HTAi Health Technology Assessment International 2018
1	Quality and Safety Summit
1	Sjogren's Society of Canada Annual Conference
1	Atlantic Mentorship Network
1	Conference Board of Canada Digital Health Integration
1	Conference Board Healthy Canada 2018
1	CHSPR- UBC Centre for Health Services and Policy Research
1	Alberta Health Services Quality and Safety Summit
Total 74	



Appendix B: Survey Questions

#	QUESTION
Q1	In what city did the conference take place?
Q2	Which conference did you attend?
Q3	Was the conference designated as “Patients Included”?
Q4	In what month did the conference start?
Q5	How did you find out about the conference?
Q6	Was it livestreamed?
Q7	How were your conference fees covered?
Q8	How were extra events covered?
Q 9	How were your travel and accommodation expenses covered?
Q10	Please comment on any issues you had with the costs of attending the conference
Q11	Did you as a patient, caregiver or member of the public feel welcome at the conference?
Q12	Did the organizers connect patients and caregivers with each other at the start of the conference? For example, a meal, a specific gathering place for patients and caregivers, previously by email
Q13	Were there other patients, caregivers or public attendees at the conference?
Q14	During the sessions, did you feel comfortable expressing your opinion, or asking questions?
Q15	Were patients included as speakers or panelists within conference sessions?
Q16	Did you feel the presentations were of interest for patients, caregivers and members of the public?
Q17	Did you have opportunities for networking with healthcare professionals/ researchers/ policy makers? (whether you took advantage or not)
Q18	Were there opportunities for networking with fellow patients, caregivers and members of the public? (whether you took advantage or not)
Q19	Was the venue, including washrooms, accessible for those with mobility issues?
Q20	Was arrival to the venue easy for you (by car, by public transportation, by mobility assisted transport, other)?
Q21	Were you asked for food requirements and restrictions beforehand?
Q22	Schedule Sensitive to any sensory disabilities and/or fatigue
Q23	Were quiet rest areas available to those who needed them?



Q24	Optional Comments About Accessibility
Q25	Were patients/caregivers involved in co-designing the conference?
Q26	Did patients/caregivers participate in the selection of the speakers and presentations?
Q27	Would you recommend that patients, caregivers and the public attend this conference next year?
Q28	What aspect of this conference meant the most to you?
Q29	What would you like to see changed for next year?
Q 30	What do you think are the benefits of attending this conference?
Q31	Is there anything else you would like to add about your experience at this conference?
Q 32	My role(s) with this conference: (check all that apply)
Q33	Have you ever worked in healthcare for pay?
Q34	I come from the province or territory of:
Q35	How many healthcare conferences did you attend in the last 12 months prior to this month?

