

Eugene Washington PCORI Engagement Award Lay Conference Summary Template

Recommended length: no more than 3 pages (not including appendices)

Background

Organization: IMPACTIVO, LLC

Name of Conference: Colloquium - Ethical Aspects of Patients' Involvement in Research: The Case for Establishing a Patient-Centered Research Agenda for Zika and Emerging Health Threats

Conference Date and Location: Friday, August 31, 2018 at Verdanza Hotel, Isla Verde-San Juan, PR

Conference Theme and Objectives:

- To revisit and train participants in Patient Centered Outcome Research as a responsible and ethical research model
- To disseminate the results of research work done related to Zika
- To share about services for pregnant women and babies with ZVD in Puerto Rico

Conference Summary

Provide an overview of the conference and highlight PCORI sessions

- The Colloquium sought to inform and promote PCOR as a new way to carry out research. Throughout our two years in the Engagement Award, our focus had been Zika, but the Colloquium tried to refocus on PCOR. The first plenary session: "Why Involve Patients in Research? Why Ask Them What Matters?" set the tone for the activity by making patients the heart of what drives research. Second, the colloquium sought to disseminate the results of the work done throughout the two years of the project by our team and share available results while also giving researchers, clinicians, patients and community members the opportunity to interact and share their experience in research efforts.

How many patients were involved, and in which stages of the planning process, for this conference?

- As P2P awardees since 2015, this Engagement Award is the result of research efforts in maternal child health and reducing preterm births branching out to Zika, which affected Puerto Rico as an emerging health threat after the Zika outbreak in 2016. Our research efforts with PCORI have been led from the start by a Leadership Team, that consist of 6 members, 2 of which are mothers and represent patient stakeholders.
- The Colloquium agenda was proposed and availed by the Leadership Team, carefully crafting the conference themes and panel subjects to ensure it be of interest to the expected audience and promote engagement. The event agenda included two breakout sessions. The first included an hour-long segment of three short sessions where attendants divided into two tracks: a track for patients and the other for researchers and stakeholders. The patient group met in close quarters, enabling them to share personal experiences and offer peer counseling. One of the segments "Know the Laws, Know your Childs Rights? A Patient's Perspective" was led by Marta Gonzalez, a mother to a now teenage boy who had many health problems at birth. The attendance of both Marta and her son were a great testimony for patient empowerment and participation. The other group (researchers and other stakeholders) focused on the innovative aspects of PCOR and how to navigate it as a research methodology, including how it differs from traditional research, how IRB applies to PCOR, and tools for measuring patient engagement. The second breakout session was planned to model how to carry out patient and stakeholder engagement.

Participants worked together developing recommendations on how to advance PCOR and at the end, they all signed a Personal Commitment to advance and defend patients' participation in research. All tables were organized to have equal representation of patients, researchers and other community and academic stakeholders. We succeeded in consistently eliciting patients' participation, with an increase of 175% from our first activity to our last.

- The Colloquium's attendance was of 91 total-19 were researchers (20%), 41 were patients (45%), and 31 were stakeholders from diverse fields and backgrounds (34%). The Colloquium put the spotlight on patient participation by highlighting the importance of involving patients in research and defining the ethical aspects of patient-centered research. Three patients participated in the planning of the colloquium, four patients facilitated or presented in sessions and 46% of the audience members were patients, participating all day long.

What role did patients and stakeholders play at the conference, and how did their engagement enhance the experience for all attendees?

- All attendees participated as equal partners in the meeting. Each person, in their own particular role, had an important perspective to bring to the conversation. All audience members benefitted from an agenda that sought to better inform on what PCOR is and how we can make a difference by doing research in a new way. Their engagement and participation enriched the experience of all attendees; particularly those of researchers who have never worked directly with patients.

Key Findings

Describe the impact and outcomes of the conference

- The meeting objectives were fulfilled and exceeded. The Colloquium agenda effectively addressed the PCOR training component, discussing ethics in PCOR, sharing successes and results of research done related to Zika and, providing information of services available to pregnant women and babies exposed to ZVD in Puerto Rico.

Describe any additional consequences or benefits of engaging patients/stakeholders in your project

- The greatest benefit of engaging patients/stakeholders in our project is how widely we have been able to reach and promote PCOR as a new research methodology. We pride ourselves as pioneers of practicing PCOR in Puerto Rico and will continue to inform on PCOR as the ethical way of carrying out research projects.
- Patients and stakeholders alike have been very vocal on their interests, ideas and their intent to keep in touch with us through our Partnership group. We believe that making all stakeholders equal participants paves the way for research done differently. We understand that their participation, with their own perspectives, helps advance PCOR as a research method on the Island.

Evaluation results and findings, including (if applicable), assessment of speakers, curriculum effectiveness, participant experience, and/or recommendations for future work

- Speakers were rated excellent. However, the conference's greatest success was creating an atmosphere where patients were not only present and participating, but the key focus of the Conference. Participants' evaluations stated that they had never witnessed this kind of dynamic. The conference was inclusive, and we believe that it served as a model to many researchers and stakeholders that there is a different and better way to approach patients and have them participate. Most patients were joined by their children and family members, strengthening the value and participation of support groups from the patients' perspective.

- *The conference atmosphere set the tone for a richer and more equitable interaction between participants. The day-long event helped participants become familiar with PCOR and provided a great example of how this interaction can come about. Another positive outcome of the conference was the Personal Commitment to advance patients' participation in research signed by attendees. Not only did they learn how to level different opinions and interests to find a common ground, but they were also able to see ahead and identify ways in which they could each work toward this goal.*

Lessons learned

- *We have learned several lessons along the way. Some are related to organizational issues; others related to patients' recruitment – timing, strategy, messages shared; and still others related to the diversity of our participants – how to accommodate and be sensitive to diversity, how to understand patients' particular needs furthermore when these patients are mothers with babies. Specifically, having families with their affected kids- cerebral palsy and microcephaly-actively participating and advocating for others was humbling to all.*
- *Evaluations showed satisfaction of the participants and most expressed feeling comfortable and in an atmosphere where patients truly had a voice. Many researchers, and even outreach personnel, expressed that they had never had such a hands-on experience with patients. It helped debunk patient participation from being mere subjects to being active participants.*

Dissemination Plans

Describe the plan to disseminate the conference proceedings

- *Colloquium proceedings once available, will be posted on Impactivo's website. Written communication to all participants will inform them on their availability and links to reach them on the Web. Information will also be prompted on social media and sent to our partners and research community, including participants of all three events. The last issue of our Zika newsletter, which reaches approximately 280 persons, will further announce the availability of the proceedings and other conference documents online, including three unplanned publications on patients' engagement. A live video of the keynote speech was streamed online and is still available on our Facebook page.*

Include any potential facilitators and/or barriers to dissemination

- *We've encountered little to no barriers regarding dissemination. We have followed a Dissemination Plan and have made sure to maintain an active presence in social media. Our contacts data base is constantly updated, and the press know and respect our research partners.*

Describe potential results to be incorporated into practice, if relevant

- *Our core area leaders are committed to continue their research efforts and Impactivo will continue to support them and share the work done within our network and platforms. Our first publication of this project, the research agenda, will guide researchers in their initiatives. Significant interest in further training in PCOR has been shown by researchers, administrators and members of the top IRB's in the island. A recently awarded grant by CMS will allow one of our Core Area Leaders to act as a PI to continue the work of our Partnership. Our proposal incorporates patient-centered practice and will serve as pilot project in various primary care centers in Puerto Rico.*

Appendixes

- *Conference Agenda*
- *Conference Bio book*
- *Participant commitment Sheet*
- *List of Attendees*
- *Evaluation Tool*