PaCE CHI Preconference Summary

On November 9, 2018, the PaCE program held a patient engagement preconference in Chicago, IL. As with other PaCE preconferences, PaCE CHI was held in conjunction with a national primary care research conference, the 2018 North American Primary Care Research Group (NAPCRG) Annual Meeting. The 45 PaCE CHI participants, were welcomed into the Hilton Hotel conference room at 8am for breakfast and for greeting both familiar faces and new. The 57 attendees included veteran and new dyads from Canada, US, and New Zealand (see below for numbers). As people began to find their seat, PaCE program manager, Jessica Sand, set the tone for the day with the official welcome and introduction to PaCE—what is PaCE, and why were we here. We continued a few PaCE traditions, including an icebreaker so that everyone could introduce themselves and the “jargon jar”. The jargon jar is a fun way to make people aware of the jargon, acronyms, and technical terminology that we tend to use without realizing it. At the beginning of the day, each PaCE participant is given 10 tickets, and each time they use jargon they put a ticket into the jargon jar. At the end of the day, those with left over tickets are entered into a raffle for a prize.

The morning continued with table discussions so that participants could get an understanding of what “patient engagement” meant to others in the group. Tables of 8-10 were tasked with discussing key concepts from patient, clinician, and researcher perspectives. Specifically, what does engagement look like for a patient on a research project and what does it look like for clinicians and researchers to have patients on their projects? After a report back from each table and a short break, we began the presentations from PaCE veterans.

The PaCE presentations in Chicago were given from the perspective of patient/researcher/clinician partnerships in different stages of their “engagement relationship”. Beginning with the “courtship” stage of the relationship, Neil Korsen and Sarah Carter spoke about capacity building with their newly funded project as part of the Rural Health Research and Delivery core of the Northern New England Clinical and Translational Research Network.
Neil and Sarah told their story about bringing their community together, including holding a PaCE Symposium, and beginning the first steps of a patient centered outcomes research project.

Next, Alan Pavilanis and Kirk Kelly gave their version of the “honeymoon” period of the engagement relationship. Alan and Kirk have been a PaCE dyad for 4 years and have been attending PaCE meetings, becoming involved in NAPCRG, and building capacity in their Montreal Community during this time. While they have found successes in their journey and have much to celebrate, Alan and Kirk have run into many barriers in their engagement relationship. Alan and Kirk gave an honest depiction of building research capacity in a community and both the obstacles and successes that are encountered on the journey.

Lastly, Jack Westfall and Maret Felzien, who have been working together in patient centered outcomes research for almost 20 years, gave their perspective of “til death do us part”. Jack and Maret taught us how they have sustained a community in Northeast Colorado with the High Plains Research Network.

During our lunch break, we continued yet another tradition of PaCE preconferences, and used this time as a networking opportunity, although everyone must sit by someone they haven’t spoken to yet that day.

After lunch, we continued the networking by breaking out into 5 groups for roundtable discussions in a World Café style. Each table had at least two PaCE veterans who led conversations on a topic over patient engagement. Everyone had 7 minutes at each table. Discussions were:

- How do I start/What are the next steps to engage patients in my project?
- How do I ensure my project is relevant to patients/community members? How do I translate the results for patients/community members?
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Community engagement in Canada

What funding opportunities are available? In Canada? In the US? For a practicing clinician and/or community member?

As everyone gathered back together, Denese Neu, a PCORI representative, gave an update on PCORI and possible opportunities for PaCE participants to get involved in PCORI.

Before we adjourned for the day, Jack Westfall and Jessica Sand spent some time demystifying the NAPCRG Annual Meeting. From past meetings, we’ve received feedback that entering the conference with its 1000+ attendees and hundreds of presentations, workshops, and forums can be quite overwhelming for those who have never experienced it. In response to this, the PaCE team has created a “mini-research” session to prepare PaCE participants for the hectic research poster presentations that they will be attending the days following the preconference. During the mini-research session, several posters are hung around the room with a “presenter” at each and we all go through a mock research poster session. At the end of the session, everyone knows how to read a research poster, what to look for on a poster, and what questions they may want to ask the presenter.

Another approach we’ve used to make the NAPCRG Annual Meeting less intimidating for the patients and clinicians of PaCE is to create a PaCE track agenda. The PaCE team searches through the hundreds of presentations that are scheduled for the Annual Meeting and pull out those that look interesting from a PCOR and engagement perspective. We then make a separate agenda with only these presentations listed. The feedback has been very positive for the PaCE track agenda and people seem to find it less overwhelming than the regular program.

As we adjourned for the day, we once again went around the room for “Last Words”. During this time, everyone shared one thing that they had learned during the preconference and how they were going to apply this to their community. As always, we ended Last Words on a patient participant.
PaCE CHI by the numbers

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Attachments to this summary include:

1) PaCE CHI Agenda
2) PaCE CHI Attendee Evaluations
3) PaCE CHI Participant List
4) PaCE CHI Track Agenda
5) Sand presentation
6) Korsen/Carter presentation
7) Pavilanis/Kelly presentation