



# Advisory Panel on Patient Engagement – Spring 2020 Meeting

**June 4-5, 2020 via GoToWebinar**

**June 4, 2020**

**Part 1:** 8:30 – 11:15 PT/ 11:30 – 2:15 ET

**Part 2:** 11:10– 11:55 PT/ 2:10- 2:55 ET

**June 5, 2020**

**Part 1:** 8:30 – 10:30 PT/11:30-1:30 ET

**Part 2:** 11:30 – 12:10 PT / 1:30 – 3:10 ET

<b>MEETING CONNECTION</b>	<p><b>GOTOWEBINAR:</b></p> <p><b>Advisory Panel Members:</b> Please connect to the meeting using the personalized link sent to you in the “Bookmark this Email -- Technical Information on the PEAP Meeting June 4-5.” This link is for both days.</p> <p><b>Public Attendees:</b> Please register using <a href="#">this link</a>.</p> <p><b>GOTOMEETING:</b></p> <p><b>Advisory Panel Members:</b> Please connect to the closed session using <a href="#">this link</a>.</p>
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# DAY ONE: THURSDAY, JUNE 4 – PART I

PACIFIC TIME	EASTERN TIME	SESSION
8:30 – 8:45	11:30 – 11:45	<b>Welcome</b> (Kristin Carman and Tom Scheid, moderators) <ul style="list-style-type: none"> <li>▪ Agenda</li> <li>▪ Platform Orientation</li> <li>▪ Roll Call</li> <li>▪ Remarks</li> </ul>
8:45 – 9:30	11:45 am – 12:30 pm	<b>Dr. Nakela Cook, Executive Director, PCORI</b> (Kristin, moderator) <ul style="list-style-type: none"> <li>▪ Remarks by Tom Scheid and Gwen Darien, followed by Q&amp;A</li> </ul> <p>Supplemental Reading Material:</p> <ul style="list-style-type: none"> <li>• <a href="#">Dr. Nakela Cook's Blog</a></li> </ul>
9:30 – 10:40	12:30 -1:40	<b>Our World, Our Work:</b> <p>COVID-19: PCORI Immediate Commitments</p> <ul style="list-style-type: none"> <li>▪ HERO Registry and Trial (Jean Slutsky)</li> <li>▪ COVID Targeted PFA, Engagement Awards, Dissemination &amp; Implementation (Joanna Siegel, Karen Martin)</li> </ul> <p>COVID-19: Frontline Perspectives (Kristin, moderator)</p> <p>Advisory Panelists:</p> <ul style="list-style-type: none"> <li>• Crispin Goytia, PCORnet Patient Partner, INSIGHT-NYC Clinical Research Network, and Program Manager of the Community Core of the Mt. Sinai CTSA</li> <li>• Maureen Fagan, Chief Nurse Executive, University of Miami Health System</li> <li>• Umair Shah, Executive Director, Harris County Public Health (Texas)</li> </ul> <p>OPEN DISCUSSION</p> <p>Supplemental Reading Materials:</p> <ul style="list-style-type: none"> <li>• <a href="#">Answering the Call on COVID-19: A Blog</a></li> <li>• <a href="#">PCORI Funds Registry and Large-Scale Study of Effectiveness of Hydroxychloroquine to Prevent COVID-19 Infection in U.S. Healthcare Workers</a></li> <li>• <a href="#">Applicant and Awardee FAQs Related to COVID-19</a></li> <li>• <a href="#">A Webinar Series Hosted by PCORI for Hospitals and Health Systems about COVID-19</a></li> <li>• <a href="#">Mark Vasquez: YouTube Video</a></li> </ul>

10:40 – 10:45	1:40-1:45	<b>Demonstration of Padlet</b>
10:45- 11:15	1:45-2:15	<b>Break</b>
<b>DAY ONE: THURSDAY, JUNE 4 – PART 2</b>		
<b>PACIFIC TIME</b>	<b>EASTERN TIME</b>	<b>SESSION</b>
11:15 – 11:55	2:15 – 2:55	<b>Advisory Panel COVID-19 Discussion (<i>continued</i>)</b> <ul style="list-style-type: none"> <li>What do you see emerging as the greatest needs in your community during this time that PCORI could help with? With respect to the type of research that PCORI's funds and our unique support of patient and community engagement, do you feel we are currently targeting community needs correctly?</li> <li>As we think about engaging more broadly, what are quick, impactful ways to involve the populations most impacted in research during these times? What community assets should we try to leverage?</li> </ul>
11:55	2:55	<b>Public Meeting Adjourns</b>

## DAY TWO: FRIDAY, JUNE 5 – PART I

PACIFIC TIME	EASTERN TIME	SESSION
8:30 – 8:40	11:30 – 11:40	<b>Welcome</b> (Kristin and Tom, moderators) <ul style="list-style-type: none"> <li>Review Agenda</li> <li>Recap of Day One</li> </ul>
8:40 – 9:10	11:40 am – 12:10 pm	<b>PCORI Reauthorization Activities – Update on National Priorities and Research Agenda</b> (Kristin, moderator) <ul style="list-style-type: none"> <li>Looking Forward: Refreshing PCORI’s National Priorities (Michelle Orza and Greg Martin)</li> <li>Overview of two new areas of research agenda outlined by Congress and additional data collection on costs (Jean Slutsky)</li> </ul> <p>Supplemental Reading Material:</p> <ul style="list-style-type: none"> <li><a href="#">PCORI’s Reauthorization Language</a></li> </ul>
9:10 – 9:25	12:10 – 12:25	<b>Building Awareness and Encouraging Use of PCORI’s Engagement Learnings</b> (Kristin, Christine Broderick, Julie Lesch)
9:25 – 10:05	12:25 – 1:05	<b>PEAPs in Action – “Current Advances in Patient-focused Drug Development”</b> Presenter: Katherine Capperella, VP, Global Patient Engagement Leader Janssen Pharmaceuticals <ul style="list-style-type: none"> <li>Discussion and Q&amp;A (Gwen Darien, moderator)</li> </ul> <p>Supplemental Reading Material:</p> <ul style="list-style-type: none"> <li><a href="#">FDA CDER PFDD Overview</a></li> </ul>
10:05 – 10:30	1:05 – 1:30	<b>Break</b>

## DAY TWO: FRIDAY, JUNE 5 – PART 2

PACIFIC TIME	EASTERN TIME	SESSION
10:30 – 11:10	1:30 – 2:10	<p><b>“Virtual Engagement: Lessons from a Cystic Fibrosis Community”</b></p> <p>Presenter: Sandy Sufian, Co-lead, Cystic Fibrosis Reproductive and Sexual Health Collaborative and Associate Professor, Disability Studies, University of Illinois at Chicago</p> <p>Discussion and Q&amp;A (Tom, moderator)</p> <ul style="list-style-type: none"> <li>What virtual engagement approaches are you seeing used with success?</li> </ul> <p>Supplemental Reading Material:</p> <ul style="list-style-type: none"> <li><a href="#">The Case for Social Distancing: Lessons from Cystic Fibrosis</a></li> </ul>
11:10 am – 12:40 pm	2:10 – 2:40	<p><b>Appreciation and Farewells</b> (Kristin and Gwen, moderators)</p> <ul style="list-style-type: none"> <li>Sonya Ballentine, Katherine Capperella, Beverly Rogers, Brendaly Rodriguez, Norah Schwartz, Tom Scheid, Freddie White-Johnson</li> </ul>
12:40 – 1:10	2:40 – 3:10	<p><b>Wrap-up</b> (Kristin and Tom, moderators)</p> <ul style="list-style-type: none"> <li>What’s Ahead</li> <li>Final reflections</li> </ul>
1:10	3:10	<b>Adjourn</b>