



## Agenda

### Advisory Panel on Rare Disease In-Person Meeting

Friday, December 14<sup>th</sup>, 2018

**9:00 AM Welcome and Setting the Stage**

Matt Cheung, PhD, RPh, Chair  
Cindy Luxhoj, MUP, Co-Chair

**9:15 AM Orientation for New Panelists**

Matt Cheung, PhD, RPh, Chair

**9:45 AM Dissemination and Implementation: Discussion with Primary Investigator Panel**

Joanna Siegel, SM ScD, PCORI, Director, Dissemination and Implementation  
Kristin Carman, MA, PhD, PCORI, Director, Public and Patient Engagement

**11:00 AM Break**

**11:15 AM PCORnet: Use Case and Leveraging PCORnet**

Keith Marsolo, PhD, Associate Professor, UC Department of Pediatrics

**12:15 PM Lunch**

**1:15 PM PCORI's Future Rare Disease Research**

Andrew Hu, MPP, PCORI, Director, Public Policy and Government Relations  
Sarah Philbin, MPH, PCORI, Program Associate, Comparative Effectiveness and Decision Sciences  
Gyasi Moscou-Jackson, PhD, MHS, RN, PCORI, Program Office, Healthcare Delivery and Disparities Research

**2:30 PM Break**

**2:45 PM Future Steps for the RDAP**

Matt Cheung, PhD, RPh, Chair

**3:45 PM Conclusion**

Matt Cheung, PhD, RPh, Chair  
Cindy Luxhoj, MUP, Co-Chair

**4:00 PM Adjourn**