



Agenda

Advisory Panel on Rare Disease In-Person Meeting

Friday, December 14th, 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