



Board of Governors Meeting via Teleconference / Webinar

Tuesday, July 21, 2015

12:00 pm – 1:30 pm ET

Board Members Present:

Grayson Norquist, MD, MSPH, *Chairperson*; Kerry Barnett, JD, *Vice Chairperson*; Debra Barksdale, PhD, RN; Francis Collins, MD, PhD; Allen Douma, MD; Alicia Fernandez, MD; Christine Goertz, DC, PhD; Harlan Krumholz, MD, SM; Leah Hole-Marshall, JD; Robert Jesse, MD, PhD; Richard Kronick, PhD; Freda Lewis-Hall, MD; Steve Lipstein, MHA; Barbara McNeil, MD, PhD; Ellen Sigal, PhD; Harlan Weisman, MD; Robert Zwolak, MD, PhD

Board Members Absent:

Lawrence Becker; Gail Hunt; Richard Kuntz, MD, MSc; Sharon Levine, MD

MINUTES

Agenda Item	Related Minutes
Call to Order, Roll Call, and Welcome - Grayson Norquist, MD, MSPH, <i>Chairperson</i> and Joe Selby, MD, MPH, Executive Director	Dr. Grayson Norquist chaired and opened the meeting, welcomed all to the meeting of the PCORI Board of Governors and read the Chair Statement on Conflict of Interest. Dr. Joe Selby reviewed the agenda for today's meeting.
Consent Agenda: That the Board of Governors approve: - June 16th, 2015 Board Meeting Minutes and - Communication and Dissemination Research (CDR) Advisory Panel Chair and Co-Chair	Dr. Norquist introduced the Consent Agenda which included the June 16 Board meeting minutes and the nomination of Lauren McCormack, PhD, MSPH as Chair, and Danny van Leeuwen, MPH, RN, CPHQ, as Vice Chair of the Communication and Dissemination Research Advisory Panel. The following motion was made and seconded: Motion: Approve each of the motions on the Consent Agenda as reflected: -- the June 16, 2015 Board Meeting Minutes; and -- the appointment of Lauren McCormack as Chair and Danny van Leeuwen as Vice Chair of the CDR Advisory Panel. <i>Approved by a majority vote of the Board by voice vote (no opposed; no abstentions)</i>
Consider for Approval: - Slate of PCORnet Phase II Clinical Data Research Networks (CDRN) Awards	Rachael Fleurence, the Program Director for PCORI's CER Methods and Infrastructure team, presented an overview of goals of Phase II, the PCORnet Phase II CDRN application process and proposed slate of awards. The proposed slate included 13 CDRNs—all

- Slate of PCORnet Phase II Patient-Powered Research Networks (PPRN) Awards <i>Rachael Fleurence, PhD, Program Director CER Methods & Infrastructure</i>	11 CDRNs from Phase I and 2 new CDRNs. Members of the Board asked questions about and discussed the review of the sustainability criterion, the review of Phase I CDRN performance, and the new CDRNs. Motion: Approve funding for the recommended slate of awards from the PCORnet Phase II CDRN PFA (see Attachment A for the slate of recommended (and awarded) CDRNs) <i>Approved by a majority vote of the Board by roll call vote (no opposed; no abstentions); 7 recused themselves.(Dr. Barksdale, Dr. Fernandez, Dr. Kronick, Dr. Lewis-Hall, Mr. Lipstein and Dr. McNeil); Dr. Levine had announced her intention to recuse herself prior to the meeting on this agenda item, but was not present for the vote. Kerry Barnett, though present for the meeting, was absent during the CDRN vote.</i> Rachael Fleurence presented an overview of the PCORnet Phase II PPRN goals, proposed slate of awards. The proposed slate included 16 PPRNs from Phase I and 5 new PPRNs. An in-depth overview of the new PPRNs was presented. Members of the Board discussed the number of patients in PCORnet, the review of Phase I PPRN performance, overall network health, and the review process resulting in 2 PPRNs funded in Phase I that were not recommended for funding in Phase II. Motion: Approve funding for the recommended slate of awards from the PCORnet Phase II PPRN PFA (see Attachment A for slate of recommended (and awarded) PPRNs) <i>Approved by a majority vote of the Board by roll call vote (no opposed; no abstentions); 6 recused themselves (Dr. Barksdale, Dr. Fernandez, Dr. Kronick, Dr. Lewis-Hall, Dr. McNeil and Dr. Norquist).</i>
Evaluation Update: PCORI Application Process - <i>Laura Forsythe, PhD, MPH, Associate Director and Diane Bild, PhD, MPH, Senior Program Officer, Clinical Effectiveness Research</i>	Diane Bild and Laura Forsythe presented an update from the Application Enhancement Workgroup, a group convened by the Scientific Oversight Committee to develop recommendations to improve the quantity of high-quality applications submitted to PCORI. Dr. Bild presented a framework that the workgroup developed to identify and prioritize issues across four key elements: important CER

	questions, trained CER investigators, perceptions of PCORI as an opportunity, and PCORI policies that facilitate submissions. The workgroup developed working hypotheses about the PCORI application process, examined the evidence available to address the hypotheses, identified what further evidence is needed, and will recommend process improvements. Dr. Forsythe presented some evidence from PCORI's Researcher Survey, indicating that most researchers are interested in engagement in research but rated PCORI's engagement requirement as challenging to meet. From PCORI's Applicant Survey, results show that applicants believe the effort to apply is high relative to the likelihood of award. A large proportion of applicant respondents agreed that the timeline to submit an application is short, especially after PCORI adopted the competitive LOI review process in Fall 2014. Next steps for the workgroup include recommending process improvements and identifying and completing additional information collection and analysis to inform future recommendations. The Board discussed the preliminary findings and the importance of the analysis and recommendations that will result from the work group.
Annual Meeting Update - <i>Bill Silberg</i>, Director of Communications and Orlando Gonzales, MPA, Chief of Staff, Engagement	Bill Silberg provided an update on the status of the Annual Meeting planned for this October 6-8, 2015. He discussed the structure and general schedule of the sessions, including the opening joint session on D&I co-hosted by PCORI and AHRQ/Academy Health. The speakers, breakout sessions, and mini-summit topics were presented as well.
Wrap up and Adjournment - <i>Grayson Norquist, MD, MSPH</i>	The meeting adjourned at 1:20 pm

**Approved by the PCORI Board of
Governors 08-18-2015**



Attachment A to the Minutes of the July 21, 2015 PCORI Board of Governors Meeting

**THE BOARD OF GOVERNORS OF
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE**

(July 21, 2015 Board of Governors Meeting)

Slate of PCORnet Phase II Clinical Data Research Networks (CDRN) Awards

Table 1. Phase II CDRN Slate Summary (new CDRNs appear bold)

Network
A PaTH Towards a Learning Health System (PaTH)
Accelerating Data Value Across a National Community Health Center Network (ADVANCE)
Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)
Kaiser Permanente & Strategic Partners Patient Outcomes Research to Advance Learning (PORTAL)
Louisiana Clinical Data Research Network
Mid-South Clinical Data Research Network
New York City Clinical Data Research Network
OneFlorida Clinical Research Network
patient-centered SCALable National Network for Effectiveness Research (pSCANNER)
PEDSnet: A Pediatric Learning Health System
Scalable Collaborative Infrastructure for a Learning Healthcare system (SCILHS)
The Greater Plains Collaborative
The Patient-Centered Network of Learning Health Systems (LHSNet)

Table 2. Slate Overview: CDRN Phase II Networks (13 projects)

PCORnet Phase II PFA	Allotted	Proposed Total Budget*	<i>Difference</i>	Average Project Budget*
CDRN—Phase II	\$113,750,000	\$110,645,975	<i>-\$3,104,025</i>	\$8,511,228

Slate of PCORnet Phase II Patient-Powered Research Networks (PPRN) Awards

Table 3. Phase II PPRN Slate Summary (new PPRNs appear bold)

Network
ABOUT Network (American BRCA Outcomes and Utilization of Testing PPRN)
AR-PoWER (ARthritis Partnership with Comparative Effectiveness Researchers) PPRN
Collaborative Patient-Centered Rare Epilepsy Network
Community and Patient-Partnered Centers of Excellence for Behavioral Health
Community Engaged Network for All
Continuation of the NephCure Kidney Network
DuchenneConnect Registry Network (DCN)
Interactive Autism Network
MoodNetwork
Patients, Advocates, and Rheumatology Teams Network for Research and Service (PARTNERS)
PCORnet Patient-Powered Research Network Phase II: ImproveCareNow Network
ABOUT Network (American BRCA Outcomes and Utilization of Testing PPRN)
Phelan-McDermid Syndrome Data Network (PMS_DN)
PI CONNECT
Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDE-PPRN)
The CCFA Partners Patient Powered Research Network
The COPD Patient-Powered Research Network
The Fox Insight Network
The Health eHeart Alliance, Phase II
The Multiple Sclerosis Patient-Powered Research Network, iConquerMS™
The National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network
The Vasculitis Patient-Powered Research Network (V-PPRN)

Table 4. Slate Overview: PPRN Phase II Networks (21 projects)

PCORnet Phase II PFA	Allotted	Proposed Total Budget*	Difference	Average Project Budget*
PPRN—Phase II	\$36,960,000	\$32,816,085	-\$4,143,915	\$1,562,670