

**MINUTES OF THE PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
BOARD OF GOVERNORS MEETING
PARK HYATT WASHINGTON, DC
SEPTEMBER 24, 2012**

MEMBERS PRESENT: Debra Barksdale, PhD, RN; Kerry Barnett, JD; Lawrence Becker, Carolyn Clancy, MD; Francis Collins, MD, PhD; Allen Douma, MD; Arnold Epstein, MD; Gail Hunt, Robert Jesse, MD, PhD; Harlan Krumholz, MD; Richard Kuntz, MD, MSc; Sharon Levine, MD; Freda Lewis-Hall, MD; Grayson Norquist, MD, PSPH; Ellen Sigal, PhD; Eugene Washington, MD, MSc; Harlan Weisman, MD; Robert Zwolak, MD, PhD

MEMBERS ABSENT: Christine Goertz, DC, PhD; Leah Hole-Curry, JD; Steven Lipstein, MHA

METHODOLOGY MEMBERS PRESENT: Jean Slutsky, Michael Lauer, MD
Participating via Conference Call: Sherine Gabriel, MD, MSc

STAFF PRESENT: Ayodola Anise, MSH; Anne Beal, MD, MPH; Lorraine Bell, RN, JD; Marla Bolotsky, Kelton Chapman, Martin Duenas, MPA; Jason Elliker, Rachael Fleurence, PhD; Desiree Frank, Lori Frank, PhD; Mark Freeman, Orlando Gonzalez, Pamela Goodnow, CPA, CGMA; David Hickam, MD; Susan Hildebrandt, MA; Gregory Martin, Kara Odom Walker, MD, MPH, MSHS; Michele Orza, ScD; Joe Selby, MD, MPH; Gail Shearer, MPP; Sue Sheridan, MBA, MIM; Bill Silberg, Natalie Wegener, Katie Wilson, RD, MHSA

GUESTS: Nancy Miller, PhD; Sanjay Modi, MS; Murieann Mageras, Sean Magers, Erica Fischer, Richard Schmitz, Mark Fleury, Laura Forsythe, PhD, MPH; Christine Lion, Jennifer Graft, Eleanor Perfetto, Karyn Rubin, Sarah Steverman, Randy Burkholder, Angela Ostron, JD; Tony Coelho, Carter Beck, George Silberman, Daniel Campion, Prasun Subedi, Barry Dalin, Kristin Viswanathan, Perry Cohen, PhD

WELCOME AND APPROVAL OF JANUARY BOARD MEETING MINUTES

Chair Washington called the meeting to order at 8:35 a.m.

Executive Director Selby noted three corrections to be made to the Minutes of the Meeting of the Board of Governors held on January 18 and 19. The corrections were as follows:

- Senior Advisor Gail Shearer was in fact present at the closed session and was misidentified as a TMC employee.
- Judy Glanz, misidentified as the Director of Patient Engagement, was in fact Director of Stakeholder Engagement at the time.
- Member Zwolak, listed as both present at and absent from the meeting, was in fact present.

Vote: Member Levine made a motion that the Board approves the corrected Minutes. The Board voted unanimously to approve the corrected Minutes.

EXECUTIVE DIRECTOR'S REPORT

Executive Director Selby presented highlights of PCORI's progress since the last Board meeting, focusing on successful recruitment of additional staff, the theme of Engagement, and an overview of the Pilot Projects.

ENGAGEMENT UPDATE AND PATIENT/STAKEHOLDER WORKSHOPS

COO Beal, Director Hildebrandt, and Deputy Director Sheridan presented PCORI's strategy and process for patient engagement, as well as upcoming stakeholder workshops. The Board discussed recommendations for reaching stakeholders who may not be part of established networks and are more difficult to reach; measures of success in engaging patients, caregivers, and stakeholders; and suggestions for how PCORI can demonstrate and lead "research done differently" for patients, caregivers, stakeholders and the research community.

TOPIC GENERATION AND RESEARCH PRIORITIZATION

Scientist Fleurence presented PCORI's approach to research topic generation and prioritization efforts, and asked the Board to discuss several aspects of the process including the appropriate level of patient and stakeholder engagement, transparency and rigor, balance of the research portfolio likely to result, and engagement between the Board of Governors and Advisory Panels.



PCORI ADVISORY PANELS

COO Beal presented the rationale for forming Advisory Panels to assist in identifying research priorities and establishing the research project agenda. Board discussion focused on the resources, particularly staff, required to form and manage these panels.

Vote: The Board voted unanimously that staff should draft charters for up to four advisory panels.

PCORI FUNDING ANNOUNCEMENT (PFA) 5A RESEARCH METHODS

Scientist Fleurence provided a brief update on PCORI Funding Announcement 5A, on research methods. It has been drafted and is scheduled for release on November 15.

STANDING COMMITTEE ON CONFLICT OF INTEREST (SSCOI): OPERATIONS PLAN FOR COI POLICY FOR METHODOLOGY COMMITTEE

Member Becker presented and the Board discussed the infrastructure for implementing the conflict-of-interest policy for the Methodology Committee, including recusal and COI disclosure, non-disclosure agreements, PCORI Funding Announcement firewalls, and an administrative bifurcation of the Methodology Committee to preserve PCORI Funding Announcement confidentiality. Next steps include development and adoption of COI policies regarding external parties, including Advisory Panels, consultants, etc.; implementation of the firewalls for the Methodology Committee; and monitoring and regular review for COI compliance.

UPDATE ON PUBLIC COMMENT PERIOD FOR DRAFT METHODOLOGY REPORT

Directors Frank and Silberg presented and the Board discussed process for obtaining and incorporating public comment on the draft methodology report. The Methodology Committee is revising the report in response to the comments received, and will deliver to the Board later this fall a revised set of standards.

FINANCE, AUDIT AND ADMINISTRATION COMMITTEE REPORT: 2012 BUDGET

Member Barnett, Chair of the Finance, Audit and Administration Committee (FAAC), COO Beal and Director Goodnow presented PCORI's 2012 budget and expectations for 2013. They discussed with the Board the intricacies of PCORI's cash flow, revenues and expenditures, and the impact of potential sequester on PCORI's revenues.



COMMUNICATIONS UPDATE

Director Silberg presented PCORI's framework for making communications decisions and discussed with the Board the evolution of PCORI's messaging, identification of and tailoring to key audiences, development and tracking of appropriate metrics. Communications process and procedures will be developed over the next several months.

SCIENTIFIC PUBLICATIONS COMMITTEE UPDATE

Director Silberg reviewed the activities of the Scientific Publications Subcommittee which expects to become much more active over the next 6-12 months. Discussion with the Board highlighted several recent notable publications in JAMA, NEJM, AIM, as well as the Health Affairs blog; development of a strategic publishing plan, and coordination with the Communication, Outreach and Engagement Committee.

PUBLIC COMMENT PERIOD

Comments were received from Lisa Simpson of Academy Health, Carter Beck of the Montana Neurological Associates, Tony Coelho of the Partnership to Improve Patient Care, Andrew Spiegel of the Colon Cancer Alliance, and Perry Cohen of the Parkinson Pipeline Project.

Chair Washington adjourned the meeting at 4:50 p.m.