

PATIENT AND STAKEHOLDER ENGAGEMENT IN RESEARCH: THE PCORI OPPORTUNITY

Heather M. Young, PhD, RN, FAAN

Sheridan Miyamoto, PhD, FNP, RN

Sarina Fazio, MS, RN

Yajarayma Tang-Feldman, MA

Madan Dharmar, MBBS, PhD

Stuart Henderson, PhD

Diane Goodman

Eric Bowser



Sigma Theta Tau International
27th International Nursing Research Congress

Stakeholder Engagement

- ❖ **Patient Advisory Workgroup**
- ❖ **Provider Advisory Workgroup**
- ❖ **Technology Advisory Workgroup**

Acknowledgements

Investigators

Heather Young (Principal Investigator)
Sheridan Miyamoto
Madan Dharmar
Yajarayma Tang-Feldman
Thomas Balsbaugh
Bridget Levich
Jay Han
Sarina Fazio (Project Manager)

Patient Advisory Board

Margaret Hitchcock
Mike Lawson
Diane Goodman
Maria Ibarra
Tarunesh Singh
Eric Bowser
Joe McCarthy

Provider Advisory Board

Tom Balsbaugh, MD
Patrick Romano, MD, MPH
Richard Kravitz, MD, MPH
Victor Baquero, MD
Deborah Greenwood, PhD, RN (Sutter Health)
Antonio (Ben) Balatbat, MD (Dignity Health)
Frederick J. Meyers, MD, MACP
Jonalyn Wallace, RN, MSN
Prasanth Suramprudi, MD
Bridget Levich, RN, MSN
Barbara Pelletreau, RN, MPH (Dignity Health)
Kameka Brown, PhD, FNP, RN (Veterans Affairs)

Collaborators

UC Davis Clinical and Translational Science Center
UC Davis Primary Care Clinics
Initiative for Wireless Health and Wellness Program
Center for Information Technology Research in the
Interest of Society

Technology Advisory Board

Mike Minear (CIO)
Kent Anderson, MS
Nick Anderson, PhD
Suresh Ram, MS
Scott MacDonald, MD
Amit Pande, PhD
Nina Amenta, PhD
Thomas Nesbitt, MD, MPH
Mike Hogarth, MD
Steven Chan, MD, MBA
Dan Weberg, PhD, MHI, RN
Jana Katz-Bell, MPH
Tod Stoltz, MBA
Kwan-Liu Ma, PhD
Matthew Lange, PhD
David Lindeman, PhD

Patient Advisory Board

Mr. Eric Bowser

Ms. Diane Goodman

Dr. Margaret Hitchcock

Ms. Maria Ibarra

Mr. Michael Lawson

Mr. Joseph McCarthy

Mr. Tarunesh Singh



Patient Advisory Board Member Perspectives on Reasons for Engaging

- ❖ **Desire to help others living with diabetes**
- ❖ **Positive experiences with research**
- ❖ **A chance to have one's voice heard**
- ❖ **Financial**

Patient Advisory Board Responsibilities

- ❖ **Advise** the research team about study design, approach and outcomes
- ❖ **Identify gaps** important to you in existing care
- ❖ **Present your views and preferences** for use of technology and integration into care
- ❖ **Pilot/test** the technology and platform- provide feedback
- ❖ **Attend quarterly meetings** (~ 2 hours each)
- ❖ **Attend conferences** to learn about latest technology and trends in care that may be useful in the project
- ❖ **Assist team** to interpret data and disseminate research findings

Patient Advisory Board Contributions

- ❖ **Advised** the research team in design
 - Survey questions and burden for participants
 - How to structure the coaching
 - Testing and feedback on technology
 - Training the nurse coaches – providing feedback on coaching
 - How to engage participants and keep them engaged
- ❖ **Assist team** to interpret data and disseminate research findings
 - Focus group data interpretation
 - Co-presenting at conferences on patient engagement in research

Key contributions for this project from advisors

- ❖ **Influencing systems:** promotes understanding of systems issues/logistics/culture so that study design aligns and addresses barriers
- ❖ **Influencing people:** credibility with expert consultation, opening doors to other stakeholders, creating a buzz and priority for the project
- ❖ **Influencing implementation:** anticipating and addressing barriers, identifying opportunities

Patient and Stakeholder Engagement

❖ Engagement at every step of the process

- ✓ Initial framing of questions, identifying important issues, study design

❖ Proposal included data from stakeholders throughout

- ✓ As background and in informing the design and methods

❖ Formal roles for stakeholders

- ✓ Advisory boards with agenda that are tied to the milestones and deliverables

❖ Payment of patients

- ✓ For time on board as well as for travel for learning and dissemination

Preparing a competitive proposal

- ❖ Engage stakeholders early and often
- ❖ Two review criteria: patient-centered outcomes and stakeholder engagement
- ❖ Recognition of patients in implementation plan and budget
- ❖ PCORI Patient Engagement Officer and direct reporting from Patient Advisory Board to PCORI

Thank you!