

## PROGRAM OF RESEARCH ON OUTCOMES FOR KIDS

STAKEHOLDER ENGAGEMENT IN TRANSLATIONAL RESEARCH PATIENTS, COMMUNITIES AND ORGANIZATIONS

#### WHO WE ARE

**Program of Research on Outcomes for Kids** (PROKids) is a health services research program within the UW Department of Pediatrics. PROKids focuses on research and quality improvement efforts to optimize health, including access to care, quality and safety of care, and outcomes from care. Although within the Department of Pediatrics, we have worked with stakeholder/patient populations of all ages, from the parents of young infants, through teens, and adults of all ages. A central theme in our activities is the engagement of stakeholders such as patients, families, multidisciplinary healthcare providers, health advocates, payers, and healthcare leadership in designing, delivering, and evaluating interventions to improve well-being.

#### WHAT WE OFFER: SERVICES

- We have done numerous one-time or ongoing consultations regarding stakeholder engagement to successful PCOR awardees (PI names on request) such as:
  - o Identified stakeholders for applicants or connected them with resources to do so
  - Made referrals to stakeholder engagement training resources on campus and across the nation
  - o Advised on selection of meaningful engagement strategies
  - o Refined materials and processes for stakeholder engagement, including engagement activities that include a diverse range of stakeholder types and backgrounds
  - o Designed appropriate budgets and timelines for stakeholder engagement
  - Shared templates for support letters for an array of stakeholder types
  - o Guided individuals through navigating IRB-related issues around stakeholder engagement
  - o Provided crucial connections to leaders in the field of stakeholder engagement
- Beyond stakeholder engagement, we also offer consultation about PCOR methods broadly.
- We recognize critical gaps in an applicant's PCOR team and make referrals to other investigators or services familiar with PCOR methodology to fill this gap.
- We have expertise in developing, validating, collecting, and analyzing measures of patient-reported outcomes, which are central to being able to understand the patient-centered impact of an intervention.

- We are skilled with operationalizing PCORI methodology standards, milestone creation, data sharing requirements and peer-review activities.
- In the post-award period, we have expertise with PCORI-specific activities such as contract execution, progress report submission, and interim progress calls.
- We share our knowledge of potential future PCOR RFA topics with investigators who are working in relevant areas, allowing them time to develop competitive applications.

### **CONTACT INFORMATION**

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### **ABOUT THE INTAKE PROCESS**

In general, it is helpful to have the applicant complete a short intake template so that we can come to the table with specific goals and questions in mind. We also ask for a CV, so we can get a sense of the investigator's background. If any written materials are available, having those in advance can make our consultation more efficient.

### STATEMENT: ARE WE A GOOD FIT FOR YOUR NEEDS?

Our program has broad expertise in facilitating stakeholder engagement across various populations, investigator types, disease states and with flexible, evidence-based methods. For example, to date, we have engaged all 7 types of PCOR stakeholders: patients, providers, payers, product makers, purchasers, policy makers, and professionals in health sciences education. Our efforts span the spectrum of health seeking behaviors such as promoting health, preventing disease, and optimally managing existing chronic disease. Our stakeholder engagement techniques are grounded in theory-based work and the PCORI stakeholder engagement rubric.

# **UW ICTR-CAP Partner Programs Supporting Stakeholder Engagement in Translational Research**

\*Center for Patient Partnerships \* Program of Research on Outcomes for Kids \* Sonderegger Research Center 
\* VA Hospital Research Program \* Wisconsin Network for Research Support \* Wisconsin Surgical Outcomes 
Research Program\*

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