Executive Search

Client Overview

Our client, Patient-Centered Outcomes Research Center (PCORI), is seeking its first Director, Patient Engagement. PCORI helps people make informed healthcare decisions and improves healthcare delivery and outcomes by producing and promoting high-integrity, evidenced-based information that comes from research guided by patients, caregivers, and the broader healthcare community. PCORI has retained Sterling Martin Associates to help with this important search.

About PCORI

The Patient-Centered Outcomes Research Institute (PCORI) was established under the Patient Protection and Affordable Care Act of 2010 (PPACA). The purpose of the Institute is to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions. PCORI will fund research and evidence synthesis that advances the quality and relevance of evidence concerning the prevention, diagnosis, treatment, monitoring, and management of diseases, disorders, and other health conditions and considers variations in patient sub-populations; and the dissemination of research findings, with respect to relative health outcomes, clinical effectiveness, and appropriateness of medical treatments and services.
The Institute will spearhead efforts to prioritize and fund comparative clinical effectiveness research (CER) using a largely stakeholder-driven process. This initiative builds upon the strong foundation laid in 2009 by the $1.1 billion in funding for CER in the American Recovery and Reinvestment Act (ARRA).

The Institute will establish and execute a national patient-centered outcomes research (PCOR) agenda by identifying research priorities and by funding and facilitating new PCOR studies. These studies will consist of both systematic reviews of existing evidence and new prospective research, including clinical trials and observational studies.

The primary duties of the Institute are to:
- Identify national priorities for research;
- Establish and update a research project agenda;
- Adopt research methodological standards developed by PCORI’s Methodology Committee;
- Contract with eligible entities for the management of funding and conduct of research;
- Disseminate the results to clinicians, patients, and the general public;
- Measure the impact of research on clinical decision-making and health status; and
- Obtain public and stakeholder input.

A variety of entities are eligible to receive funding contracts, including federal agencies, academic institutions, and private research organizations. The Agency for Healthcare Research and Quality (AHRQ) and the National Institutes of Health (NIH) will receive priority funding consideration. Data collected by the Centers for Medicare and Medicaid Services (CMS) will be made available to the Institute and its contractors, and the Institute may request data from other federal, state, and private entities hosting patient registries and other databases.

A standing Methodology Committee has been established to lead efforts to identify and refine methodological standards for different types of CER study designs, such as pragmatic clinical trials, randomized controlled trials, and patient registries. The 17-member committee is composed of experts in comparative effectiveness methods, biostatisticians, epidemiologists, health services researchers, and others. The Committee must begin releasing methodological standards for conducting CER within 18 months of the establishment of the Institute. These standards must be adopted by the Board of the Institute and will be used to select proposed studies for funding and to guide researchers as they design studies. In addition, the Committee will develop tools to help researchers to determine which methods are most appropriate for a particular research question.

The Institute may form a number of advisory panels to assist in identifying research priorities, establishing the research project agenda and for other purposes. These panels will include practicing and research clinicians, patients, and experts in scientific and health services research, health services delivery, and evidence-based medicine, and as appropriate, experts in integrative health and primary prevention strategies. Notably, the Health Reform Bill requires the Institute to provide patients and consumers with the extra support, tools, and resources necessary to be effective members of these advisory panels. In addition, there will be public comment periods to allow the general public to provide feedback to the Institute on proposed priorities and other key decisions prior to adoption by
the Institute, in an effort to make the work of the Institute and advisory panels as transparent as possible.

Research findings must be released by the Institute to the general public no later than 90 days after they are available. The Office of Communications and Knowledge Transfer at AHRQ is also tasked with broadly disseminating the research findings, with assistance from NIH. This will include consultation with medical and clinical associations to ensure that findings are translated into clinical decision support tools.

The Institute's staff will be led by an Executive Director, reporting to PCORI's Board of Governors, which includes the directors of NIH and AHRQ, and representatives of patients, consumers, physicians, nurses, hospitals, private payers, drug and device industries, quality improvement organizations, and other federal and state health agencies. The Comptroller General of the United States has appointed members to the Board for initial terms of two to six years and has designated a chair and vice chair. Thereafter, all subsequent appointments are for six-year terms.

The Institute will be funded through the Patient-Centered Outcomes Research Trust Fund (PCORTF), which will consist of the following funding streams: for 2010-2012, PCORI funding will amount to $210 million from general revenues; for 2013, PCORI funding will be general revenues of $150 million plus an annual $1 fee per Medicare beneficiary transferred from the Medicare Trust Fund plus a $1 fee per individual assessed on private health plans; for 2014-2019, PCORI funding will be general revenues of $150 million plus a $2 fee per Medicare beneficiary plus a $2 fee per privately insured individual. By 2015, total annual funding for the Institute will reach nearly $500 million. Each year, 20% of PCORI funding shall be transferred to the Department of Health and Human Services to support AHRQ’s responsibilities under the Patient Safety and Quality Improvement Act of 2005, specifically referencing the Office of Communications and Knowledge Transfer.

The Role of Patient Engagement

What will make PCORI unique among research organizations is expressed in the last phrase of its mission statement: “... guided by patients, caregivers, and the broader healthcare community.” PCORI’s Board of Governors believes that engagement of patients and other stakeholders is essential to realize the Institute’s full potential to be a credible, trusted source of information for patients, caregivers, providers and others. The Patient Engagement function is charged with opening new and effective channels of two-way information exchange and promoting the patient’s voice in decision-making about how best to generate and provide better information. PCORI’s independence and commitment to patient engagement in all aspects of its work, coupled with a promise to apply the highest standards of scientific rigor and integrity to its research, positions the Institute to identify and fill important knowledge gaps confronting patients, clinicians, and policy makers.

Engagement is an essential aspect of PCORI’s work, extending well beyond the simple notion of securing input from a variety of stakeholders. PCORI involves patients, caregivers, and other stakeholders in a true partnership of shared accountability and ownership of PCORI’s priorities,
research agenda, and research questions, design, and processes. Consensus development will accelerate dissemination, increase acceptance, and drive demand for PCORI’s work products.

**Director, Patient Engagement**

The Director, Patient Engagement is a key member of the senior management team. He or she will report to PCORI’s Chief Operating Officer and work in close cooperation with the Director, Stakeholder Engagement and Director of Communications. The position is located in the greater Washington, DC metropolitan area.

**Key Areas of Responsibility**

- Work directly with patients and other consumers of health information, their caregivers, and advocacy organizations covering a wide variety of disease and health care settings.
- Primary responsibility and accountability to obtain, synthesize, and facilitate representation of the views of all people who use healthcare information and services to the PCORI staff and Board of Governors.
- Develop, maintain and support networks, convene advisory panels and utilize other vehicles as appropriate to capture and incorporate the perspectives of patients and caregivers into PCORI’s priorities, research agenda, and dissemination and communication efforts.
- Establish processes and coordinate patient/caregiver/consumer feedback on PCORI priorities, research, results and dissemination plans.
- Serve as the primary PCORI liaison to patient and caregiver constituencies and be responsible for regular communication with, and input from, patients and their advocates.
- Work closely with the Board of Governors’ Communications, Outreach and Engagement Committee (COEC), and with PCORI Directors of Communication and Stakeholder Engagement.
- Organize, coordinate and manage logistics of discussion forums and other events with patients and caregivers that afford interaction with PCORI Governors, Methodology Committee members, PCORI staff, PCORI grantees, and other stakeholders.
- Oversee the development of tools and support mechanisms to enable the full participation of patients, caregivers, and other consumers on PCORI advisory panels.
- Collaborate with PCORI scientists and other researchers in studying, evaluating, and improving the processes used by PCORI in engaging stakeholder communities.

**The Director’s First Two Years’ Critical Success Factors**

- Identify and/or develop robust and functioning patient/caregiver/consumer networks representing a wide variety of health and healthcare needs.
  - Determine the types and sources of patient participation on PCORI networks and panels.
  - Develop a process to populate all identified networks and panels with qualified individuals.
  - Create and gain Executive Director and Board approval of a mission and charter for each panel and network.
o Develop training, support tools, and other resources necessary for patients and consumers to be effective members of advisory panels.

- Establish best practices and develop creative strategies to encourage and foster patient engagement within different aspects of PCORI’s research processes and dissemination activities.
- Develop channels through which patients, other consumers, caregivers, and their representatives can proactively communicate with PCORI.
- Create demonstrable quantitative and qualitative measures of patient/caregiver group engagement in patient-centered outcomes research (PCOR).
- Collaborate with the Methodology Committee, as appropriate, in their work on advancing the science of PCOR.
- Identify and engage key constituents to provide regular input as PCORI develops national priorities for research.

**Desired Professional Experience, Qualifications, and Education**

- Bachelor’s degree or advanced degree in healthcare, social science, or public policy/government relations/communications disciplines (e.g. psychology, education/health education, medical, nursing, public health, sociology, public affairs, communications or related disciplines).
- Five to ten years progressive experience and demonstrated success in patient advocacy, policy, patient/consumer relations.
- Excellent negotiation, facilitation, mediation, and speaking skills.
- Experience working successfully with governing boards and committees.
- Specialized and well-developed communication skills, deployed successfully with multiple, diverse constituencies.
- Familiarity and interest in use of social media for outreach and communication.
- Deep understanding of the patient’s perspective and experience interacting with the healthcare system.
- Experience working effectively with disadvantaged and under-represented communities.
- Familiarity with evaluation and research methods highly desirable.

**Compensation**

A competitive compensation package will be offered to attract an outstanding candidate.

*PCORI is an equal opportunity / affirmative action employer committed to cultural diversity in the workplace.*
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