



Charter of the Advisory Panel on Patient Engagement

Purpose

The Advisory Panel on Patient Engagement (“PE Panel”) will advise and provide recommendations to PCORI’s Board of Governors, Methodology Committee, and staff to help plan, develop, implement, improve, and refine efforts toward meaningful patient-centered research. The PE Panel will not serve in an official decision-making capacity, but its recommendations and advice will be taken into consideration by the Institute’s Board of Governors, Methodology Committee, and staff.

Members of the PE Panel will assure the highest patient engagement standards and a culture of patient-centeredness in all aspects of the work of PCORI.

The designated individual tasked with overseeing the Patient Engagement Panel’s activities is the Director of Patient Engagement or the individual designated by PCORI’s Chief Engagement and Dissemination Officer.

Authority

PCORI’s Advisory Panels are governed by the provisions of Public Law 111-148, which sets forth standards for the formation and use of Advisory Panels by PCORI.

PCORI’s authorizing legislation allows the Institute to appoint permanent or ad hoc expert Advisory Panels as determined appropriate to assist in identifying research priorities and establishing the research project agenda. Based on explicit directives in the law, PCORI has appointed a permanent expert Advisory Panel for Clinical Trials and a permanent expert Advisory Panel on Rare Diseases. Furthermore, PCORI appoints other permanent and ad hoc expert Advisory Panels when there is a demonstrated need.

Function and Scope of Work

Patient engagement in research is the involvement of patients, caregivers, and patient and caregiver advocacy organizations in all aspects of the research process. By inviting the patient and caregiver community to help generate research questions, review research proposals, assist in the conduct of research, help disseminate information and evaluate impact, patient engagement assures authentic patient-centeredness in the research process.

The PE Panel will:

- Advise on processes to identify research topics and priorities that are important to patients;
- Advise on all aspects of stakeholder review of applications for PCORI funding relating to patient engagement;
- Provide general recommendations to PCORI and externally on the conduct of patient-centered research;
- Advise on methods to evaluate the impact of patient engagement in research;
- Assist and advise PCORI on communications, outreach, and dissemination of research findings; and
- Provide advice on other questions and areas of interest that may arise relevant to PCORI's mission and work.

Composition and Structure

PCORI aims to involve patients, caregivers, clinicians, other stakeholders, and the organizations representing these stakeholders in a partnership of shared accountability for PCORI's research priorities and research agenda. Membership on the PE Panel will allow for meaningful interactions amongst individuals with different strengths, backgrounds, and areas of expertise.

The PE Panel will consist of 12 to 24 members appointed by the PCORI Board of Governors. No fewer than 60 percent of PE Panel members will be selected from persons who are patients, caregivers, or representatives of patient advocacy organizations. The remainder will include representation by clinicians and clinician organizations, organizational providers, employers, health insurance plans, the life sciences industry, policy makers, and clinical researchers.

A Chair (and a Co--chair if desired) will be selected by the Institute's Board of Governors to facilitate the PE Panel's activities in conjunction with the Institute's Director of Patient Engagement. The Chair may assemble subcommittees composed of PE Panel members to examine special issues and to facilitate activities related to the scope of work described in this charter.

Members will serve three year terms. Terms shall be staggered with a goal of having a balanced number of members appointed each year and a diverse spread of members. To implement staggered terms, initially some members will be appointed for a one--year term, some for a two--year term, and some for a three--year term. Members will not serve more than one full three--year term. Panel participation will not be extended beyond the life of the PE Panel's complete work and charter. Any member may resign at any time by giving written notice to the chairperson of the PE Panel. Vacancies will be filled at the discretion of PCORI's Executive Director.

Management and support services will be provided by PCORI staff and contractors.

Panelist Applications and Selection

PCORI will initiate an open call for applications via the PCORI web site and other modes of communication when it is seeking members for an Advisory Panel. Prospective panelists are invited to submit an application via an online portal to be considered for a position on the PE Panel.

PCORI strives for inclusiveness and diversity in age, ability, gender, ethnicity, race, sexual orientation and gender identity, education, socioeconomic status, and geography in the selection of panelists.

The application review and panelist selection process for the PE Panel will be based on experience, background, ability to contribute to the scope of work described in this charter, and a prospective panelist's commitment to advancing the mission and goals of the Institute

The Institute's Board of Governors will have final approval of the PE Panel's membership roster.

Meetings

Meetings shall be conducted in an open forum and records of the proceedings kept in accordance with PCORI's policies and procedures. All meetings will have an agenda, which will be issued to panelists and made available to the general public at least three business days prior to the meeting.

Meetings of the full panel will be called by the Chair with the agreement and consent of PCORI's Director of Patient Engagement, who shall develop and approve the agenda and be present at all meetings. Notice of all meetings shall be given to the public at least three business days before the meeting is set to occur.

A majority of the members of an advisory panel shall constitute a quorum, and a roll call must be taken at the beginning of each meeting. In accordance with the PE Panel's advisory role, all votes and recommendations are nonbinding to the Institute.

Compensation, Travel, and Expenses

Members who are not full-time Federal employees are eligible for compensation. The amount of compensation shall be set by PCORI's Executive Director, based on the nature and amount of services to be provided and consistent with applicable PCORI policies and procedures.

Travel and other expenses incurred during the conduct of PCORI business will be paid for by the Institute only if the expenses are reasonable and they comply with PCORI's policies and procedures.

All payments will be made to individual panel members and not to employers, organizations, or third parties. Individuals serving on an advisory panel may decline compensation or reimbursement of expenses at their discretion.

Conflict of Interest

All PE Panel members shall abide by the Institute's Conflict of Interest Policy. Members will be asked to disclose any potential conflicts upon joining the PE Panel. Each panel member shall work with the Institute's Executive Director or designee to identify conflicts to consider for appropriate actions so that a panelist does not participate in matters when a conflict exists.

In general, appointment to the PE Advisory Panel will not lead to ineligibility for funding because: all meetings will be public; members will not have access to confidential, nonpublic information; and panelists will provide input, but will not be responsible for final decisions.

Termination Date

This charter will remain in effect until terminated by the Board of Governors. It is subject to review, reauthorization, amendment, or termination by the Board of Governors or its designee. This charter will be reviewed on an annual basis.

History:

Approved by the PCORI Board of Governors 4/1/2013

Amended and approved by the PCORI Board of Governors 5/6/2013

Amended and approved by the PCORI Board of Governors 12/3/2013

Amended and approved by the PCORI Board of Governors 4/26/2016

Amended and approved by the PCORI Board of Governors 7/18/2017