



Charter of the Advisory Panel on Healthcare Delivery and Disparities Research

Purpose

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

PCORI’s mission is to help people make informed healthcare decisions and improve healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community. PCORI’s five National Priorities for Research serve as a framework for guiding PCORI funding to fulfill PCORI’s mission. The HDDR Panel will provide practical guidance relating to two of PCORI’s National Priorities for Research: Improving Healthcare Systems and Addressing Disparities.

Research on healthcare delivery systems and disparities addresses critical decisions about improving the delivery and equity of care faced by healthcare system leaders and policy makers, clinicians, and the patients and caregivers who rely on them. PCORI’s Healthcare Delivery and Disparities Research program funds studies that: compare the clinical effectiveness of alternative features of healthcare systems that are intended to optimize the quality, outcomes, and efficiency of care for patients; and will inform the choice of strategies to eliminate disparities, in health, and healthcare outcomes. The knowledge from this research will provide insight about the comparative benefits and harms of the options and provide information about outcomes that are experienced by patients and important to patients, including possible differences in outcomes across patient subgroups.

Authority

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

PCORI’s authorizing law allows PCORI to appoint permanent or ad hoc expert Advisory Panels as determined appropriate to assist in identifying research priorities and establishing the research project agenda and for other purposes. Based on directives in the authorizing 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

In support of its purpose, the HDDR Advisory Panel will:

- Identify critical research questions and topics for possible funding initiatives under PCORI's Healthcare Delivery and Disparities Research program that are germane to the generation and use of evidence for improving healthcare systems and addressing disparities;
- Provide stakeholder inputs and refinements on PCORI research priorities, questions, and topics;
- Provide ongoing feedback and advice on priorities for communicating and disseminating the research findings under the HDDR program;
- Review and comment periodically on PCORI's research portfolio, including the identification of important gaps in the portfolio, how to communicate the portfolio to different stakeholder groups, and the overall impact of the portfolio;
- Consider study findings in terms of relevance to stakeholder groups, and advise on targets and strategies for PCORI dissemination and implementation efforts; and
- Provide feedback and refinements to PCORI on specific research questions and study designs relating to healthcare systems and disparities.

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 HDDR Panel will allow for meaningful interactions amongst individuals with different strengths, backgrounds, and areas of expertise.

The HDDR Panel is formed through the combination of two prior PCORI Advisory Panels: The Advisory Panel on the Improving Healthcare Systems and the Advisory Panel on Addressing Disparities. After a transition period during which the previously appointed members of these two prior Advisory Panels serve their appointed terms on the HDDR Panel together, the final, single HDDR Panel will consist of 12 to 24 members appointed by the PCORI Board of Governors. No fewer than 25 percent of HDDR 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.

Two co-chairs will be selected by PCORI's Board of Governors from among the HDDR Panel members to facilitate the HDDR Panel's activities in conjunction with PCORI's designated Scientific Program Director or designee.

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. Members will not serve more than one full three-year term. Any member may resign at any time by giving written notice to the co-chairs of the HDDR Panel. Vacancies will be filled at the discretion of PCORI's Executive Director.

The co-chairs may assemble subcommittees composed of the HDDR Panel's members to examine special issues and to facilitate activities related to the scope of work described in this charter.

The designated individual tasked with overseeing HDDR Panel activities is the Scientific Program Director for HDDR or the individual designated by PCORI's Chief Science Officer. 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 HDDR 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 HDDR Panel will be based on experience, background, ability to contribute to the scope of work described in this charter, a prospective panelist's commitment to advancing the mission and goals of PCORI, and will be guided by the desire to balance expertise for both the Improving Healthcare Systems and Addressing Disparities PCORI national research priorities.

PCORI's Board of Governors will have final approval of the HDDR 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 co-chairs with the agreement and consent of the designated Scientific Program Director or his/her designee, who shall develop and approve the agenda and be present at all meetings.

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 HDDR Panel's advisory role, all votes and recommendations are nonbinding to PCORI.

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 or his/her designee, 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 PCORI 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 HDDR Panel members shall abide by PCORI's conflict of interest policies. Members will be asked to disclose any potential conflicts upon joining the HDDR Panel. Each panel member shall work with PCORI's Executive Director or designee to identify conflicts and to consider appropriate actions so that a panelist does not participate in matters when a conflict exists.

In general, appointment to the HDDR 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 12/12/2017

- *The HDDR Panel was formed based on a merger of the prior Advisory Panel on Improving Healthcare Systems Research (originally approved by the PCORI Board of Governors on 4/1/2013 and sunset by the PCORI Board of Governors on 12/12/2017) and the prior Advisory Panel on Addressing Disparities (originally approved by the PCORI Board of Governors on 4/1/2013 and sunset by the PCORI Board of Governors on 12/12/2017).*

Amended and approved by the PCORI Board of Governors 6/19/2018