

# Elevating the Patient Voice in Research



Health & Medicine  
POLICY RESEARCH GROUP

## Project Summary

**Background:** In August of last year [CAPriCORN's](#) Patient Community Advisory Committee (PCAC) and [Health & Medicine Policy Research Group](#) was awarded a Eugene Washington [PCORI](#) Engagement Award for Conference Support. This funding enables PCAC and Health & Medicine to plan and implement the “*Elevating the Patient Voice in Research*” project, which is designed to increase patient participation in research and to guide future health research priorities.

The project team’s plan is to ensure that patients and the public have information they can use to make informed healthcare decisions, using evidence-based information that comes from research guided by patients, caregivers, and the healthcare community. This project is focused on two of PCORI’s five strategic pillars: engagement and dissemination.

**Proposed Solution to the Problem:** The project team will engage a broad-based stakeholder community, consisting of patients, caregivers, and clinicians to generate topics for research, help the institute prioritize those topics, and ensure patient involvement in research design. The team will draw on the expertise of its partners to launch three input sessions in Chicago communities with the highest health needs, with the goal to host a culminating community conference. The team’s primary focus area is Cook County.

**Objectives:** The activities of this project will result in data, recommendations, and organizational structures to: enhance long-term internal and external stakeholder commitment to appropriate, quality health care for all; synthesize perspectives across stakeholder groups, prioritizing patient/consumer input and voice; guide future research by developing community-response research priorities for CAPriCORN’s data set; and identify and document current health system weaknesses and strengths.

**Activities:** This project will take place in as follows:

- ❖ **Start-up and Planning:** This phase will focus on establishing a 10-member planning team to guide project implementation and client engagement. The team will oversee design and implementation of the project including all planned community events and development of the final report.
- ❖ **Implementation:** During this phase, efforts will be focused on information gathering through three consumer input sessions and a day-long conference. The project will implement extensive outreach to organize participation in the information gathering process relying on the community connections of the team's many partners to engage diverse Cook County communities.
- ❖ **Analysis and Reporting:** During this last phase, the team will analyze and synthesize data collected in the implementation phase and produce and disseminate a report on provider, client, and stakeholder input and perspectives.
- ❖ **Outcomes and Outputs:** There will be a full-day community convening on **April 16, 2020 at Malcolm X College**, at which findings to date will be disseminated to the larger stakeholder/consumer community. [Register here!](#)

#### **Patient and Stakeholder Engagement Plan:**



There will be patient and stakeholder project in all phases of the project. The planning team will guide project implementation and client engagement throughout each phase of the project. The team will include members of the PCAC as well as representatives from partner organizations, the healthcare sector, patients, and other community stakeholders.

This team will oversee all aspects of project design and implementation. The team will also leverage their existing relationships with other affiliated institutions and community organizations.

**Project Collaborators:** PCAC, Health and Medicine Policy Research, Pastors 4 PCOR, the Thapelo Institute, Inc., UI Health, Westside Institute for Science and Education, and AllianceChicago.

#### **Project Details**

**Project Lead** - Joseph M. Harrington, CAPriCORN PCAC Co-Lead

**Organizational Lead** - Health and Medicine Policy Research Group

#### **For more information**

Email: [info@hmprg.org](mailto:info@hmprg.org);

Call: (312) 372-4292; or

Visit: <https://www.capricorncdrn.org/patient-engagement/>

Register for the April 16th community Input Session at Malcolm X College here:

<https://hmprg.z2systems.com/np/clients/hmprg/eventRegistration.jsp?event=726&>