



# 2019 NHC Programs



By working with all stakeholders, the National Health Council get things done to improve the health of people with chronic conditions – helping them to live longer and feel better. Our core membership includes the nation’s leading patient advocacy organizations, which control our governance and policy-making process. To achieve our mission – providing a united voice for people with chronic diseases and disabilities and their family caregivers – we rely on a broad base of support. Below is the list of current activities and programs.

## Patient Engagement

Integrate the patient voice into medical product development, research, and health care decision making:

- Produce and submit suggested language for FDA guidance documents
- Convene a dialogue on Clinical Outcome Assessment (COA), including patient-reported outcomes
- Develop a patient-engagement rubric

## Patient-Journey Mapping Toolbox

Ensure the patient’s journey is collected in a way that informs patient-centric efforts:

- Develop a patient-friendly process that captures real-world experiences
- Develop supporting materials such as an interview guide
- Create a user guide
- Disseminate to encourage standardized approaches

## NHC Marque Conferences

- **2019 Science of Patient Engagement Symposium** in October provides a rare opportunity for medical and research leaders from patient organizations, nonprofit health groups, and industry to connect, communicate, and network about the science of patient engagement.
- **2019 Washington Representatives Retreat** in November gathers government relations staff from non-profit members to address strategic, operational, and policy development issues emerging in health care.
- **2020 Health Leadership Conference** in February gathers CEOs, Board leadership, and staff from NHC members to address emerging health policy and organizational management issues and how their organizations can best prepare for the future.

## Personalized Care Management

Explore a new focus on delivering individualized care that is affordable, sustainable, and of the highest value:

- Convene stakeholders for a discussion on how to tackle fundamental changes to the health care ecosystem that enhance personalized care management
- Publish a white paper outlining next steps from the stakeholder meeting

## NHC Center of Educational Excellence to Build Patient Organization Capacity

Create a free e-learning platform with training and tools on:

- Real-World Evidence
- Clinical Outcome Assessment (COAs)
- Health Economics and Value Assessment
- Advocacy for Patient Groups
- New, timely topics



## The Patient Perspective on the Value of Treatments

Ensure the voice of the patient is an integral part of the value discussion:

- Develop intermediate education module on health economics and value
- Develop tools to explain the complexities of “value,” such as infographics
- Convene a dialogue on patient-centered value assessment between patient groups and employers
- Update the NHC Value Model Rubric and Get-Ready Check List
- Promote understanding of the QALY, its uses, limitations, and impact on patient access to guide patient-centered decision-making and methods improvements

## Fair Market Value (FMV) Calculator for Patient Compensation

Support sustainable agreements between stakeholders and the patient/caregiver community:

- Develop an FMV calculator for compensating individuals and patient groups for their work in patient-focused medical product development, research, and other activities
- Adapt European Conflict of Interest Principles for U.S. use
- Adapt contract templates to simplify and standardize the legal process for patient and patient groups for U.S. use

## Emerging Issues

Enable the NHC to nimbly respond to an ever-changing health policy environment including:

- Address the rapid acceleration of barriers to access as part of policy proposals
- Promote sustainable, affordable, high-value health care to legislators and regulators
- Educate NHC members on a variety of public policy issues such as reauthorization of PCORI or the User Fee Acts