



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