

# Update: Amplifying the Patient and Caregiver Voice

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# Prioritizing Initiatives to Amplify the Patient and Caregiver Voice

#### Recruit

 Improve patient and caregiver representation on CDP and other committees.

#### **Improve**

 Enhance NQF policies, procedures, and initiatives to lead to sustained and high-quality patient engagement.

#### Prepare

 Provide resources and education to assist patients and caregivers to best contribute to NQF processes.

### **Patient & Caregiver Engagement Advisory Council**

 QM has created a Patient and Caregiver Engagement Advisory Council to advise the department on enhancing our patient engagement activities.

### Council Objectives:

- » Assist in setting QM priorities for patient engagement initiatives
- » Provide input and feedback on strategies to recruit patients onto QM committees and assist in recruitment and retention activities.
- » Provide input and feedback on strategies to overcome barriers to participation and prepare patients and caregivers to participate successfully in the technical aspects of the committee and project work (e.g., education curriculum)
- » Provide guidance on shaping QM activities and processes (e.g., criteria, process improvements, Committee activities) to incorporate the patient and caregiver perspective

### **Patient & Caregiver Engagement Advisory Council**

- Council activities may include:
  - Providing feedback on patient-facing documents or communication
  - Reviewing patient and caregiver education curriculum
  - Participating in outreach to patient groups, organizations, or individuals.
- The council was seated via a public Call for Nominations, which was open from February 28 to April 1
  - NQF received 23 nominations, 14 selected
    - » Over 150 nominations for patient advocates submitted across this effort and the Patient-Centered Planning Project
  - Quarterly or bi-monthly calls/web-meetings

### **Patient & Caregiver Engagement Advisory Council**

- Advisory Group Composition:
  - Wide-ranging experience on patient engagement in healthcare and quality measurement
  - Existing patient/caregiver representatives on Standing Committees
  - Wide range of professional backgrounds including writers, nurses, health service researchers, and professional patient and caregiver representatives
  - Individual patient and caregiver advocates, many new to NQF
  - All are passionate about engaging patients and caregivers in quality measurement
- First meeting (orientation) of the Advisory Council is scheduled for April 24th.

## CDP Patient and Caregiver Committee Member Mentorship Program

Expected to launch a pilot summer 2019

## Program Goals

- Provide new patients/caregivers serving on CDP standing committees an opportunity to connect with experienced committee members to address questions and provide support in their new role.
- Ensure patient/caregiver participation by equipping all new patient/caregiver representatives with the necessary knowledge of the CDP.
- Further engage experienced patient and caregiver representatives to encourage continued participation.

### **Improving Patient Recruitment**

Review of the remaining nominees not selected for the patient and caregiver advisory group and patient-centered planning project

- Identify existing or upcoming projects for participation
- Collaborate with NQF membership team to identify mechanisms to maintain engagement
- Tracking patient and caregiver nominees for participation in ongoing work

## Facilitation Training on Engaging Patients and Caregivers

QM has updated facilitation training sessions to include content on patient engagement.

- Trainings for committee co-chairs and NQF staff now include specific content targeted at soliciting the patient voice.
- CDP co-chair facilitation training January 2019
  - Engaged, very supportive
  - Some recommendations for engaging patient
    - » Co-chair/patient rep. measure evaluation prep calls each cycle
    - » Identifying specific opportunities in discussion of importance and usability criteria for patient rep to contribute

## Facilitation Training on Engaging Patients and Caregivers

### **Early Success Stories**

- Patient Experience and Function
  - "Patients are built into the name of the Committee. We had better be getting this right."
- Surgery
  - "It was pretty powerful to have a patient at the table to tell us what patients want rather than developers and others speaking for them."

### Additional QM Policies on Patient Engagement

- All CDP, MAP, and relevant framework committees to include a minimum of two patients and/or caregivers
  - Aim to accomplish by the conclusion of the fall 2019 nominations period
- Patient and caregiver friendly educational materials
  - QM education team has updated NQF committee materials to be more patient friendly, clearer, and reduce unnecessary jargon.
- Honorarium policy
  - Eligible patients and caregivers can apply for honorariums to support sufficient participation of diverse Patient & Caregivers on NQF committees
    - » This initiative is in the final approval and implementation stages and is anticipated to launch in September 2019 for QM projects.

### **CSAC** Discussion

- Which priorities or initiatives should the patient and caregiver engagement advisory group focus on first?
  - Are there specific suggestions for topics of discussion for this group as we set the agenda?
- Are there other goals with patient engagement and recruitment that should be considered (in addition to seating 2 per committee)?