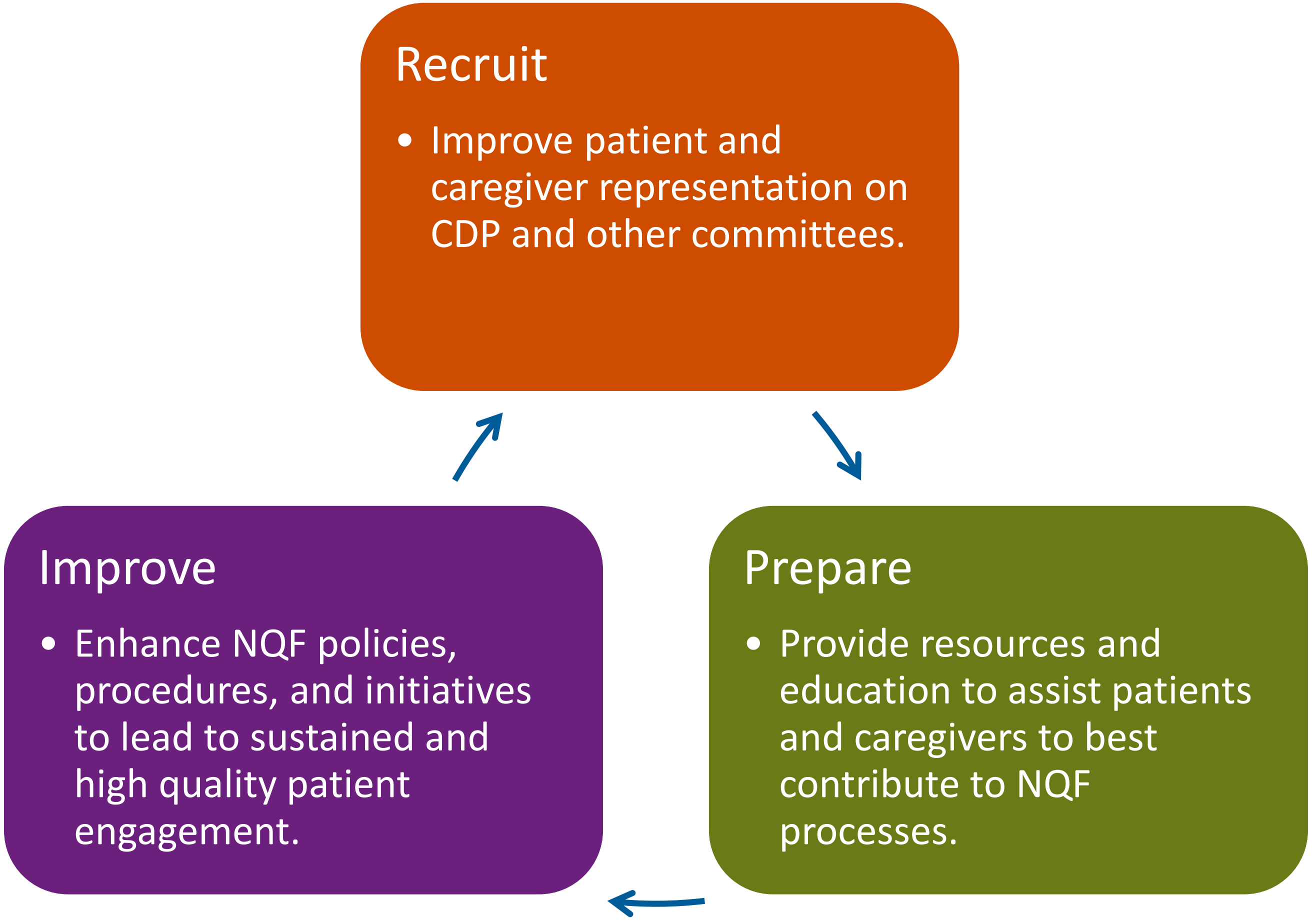
NATIONAL
QUALITY FORUM

Update: Amplifying the Patient and Caregiver Voice

Key Takeaways for Successful Engagement

- Mitigate barriers to participation and create a welcoming experience
- Prepare Patients and Caregivers for a successful experience by providing training and support that enables meaningful participation
- Ground committee work and outputs in real experiences to demonstrate that Patient and Caregiver voices matter

Prioritizing Initiatives to Amplify the Patient and Caregiver Voice



Recruit

- Improve patient and caregiver representation on CDP and other committees.

Prepare

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

Improve

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

NQF Patient Engagement: Recruit

In Process

- **Pursue honorariums to remove financial barriers to participation***
- **Share best practices for patient outreach/recruitment informally across project teams***

Next

- Explore enhancing remote participation options for patients and caregivers without compromising quality of engagement.
- Explore opportunities to increase recruitment and establish a pipeline to diverse patients and caregivers (e.g. PCORI, Patients Like Me, CUE, WEGO Health), etc.

Then

- Pursue additional funding to support patient and caregiver participation and engagement
- Explore creating a web presence for recruiting patients & caregivers
- Explore mechanisms for ongoing capture of interested patient contact information and recruit interested patients during nominations periods

*Items on which QM has made progress since the last CSAC update

NQF Patient Engagement: Prepare

In Process

- **Facilitation training for NQF staff and Committee co-chairs to better incorporate patient and caregiver voice***
- **Facilitate ongoing conversation between patient and caregiver participants currently serving on committees through group meetings and informal mentorship program to discuss and help resolve barriers to participation***

Next

- Determine how to provide Partners access to library of resources and a “Get Started” plan
- **Evaluate Partner mentorships and/or “clubs” to build camaraderie and enable participants to share experiences***

Then

- Pursue a curriculum to acclimate new patients to NQF's work, including educational meetings (and recordings), support resources, process instructions, terminology glossary, and tip sheets designed to orient/support patients and caregivers to the processes and terminologies
- Pursue re-designing orientations to specific audiences and conduct warm-up measure evaluations to orient new participants

*Items on which QM has made progress since the last CSAC update

NQF Patient Engagement: Improve

In Process

- **Establish goals and work plan for NQF patient engagement activities, including goals for all CDP Committees to include a minimum of two patient and/or caregivers on each active Committee***

Next

- Communicate processes and standards to help audiences understand Patient & Caregiver initiatives
- Standardize/clarify vernacular
- Explore how processes and deliverables can better capture the patient and caregiver voice

Then

- Consider potential changes to session design, including evaluation criteria and CDP processes to optimize patient contributions.
- Evaluate creating a web presence that highlights patient & caregiver engagement and showcasing shareable stories (as appropriate)

*Items on which QM has made progress since the last CSAC update

Increasing Patient Recruitment

New QM Policies on Patient Engagement

- Includes an operational definition of Patients and Caregivers for NQF purposes
  - **Patients:** Persons who have direct experience, either currently or in the past, with an illness or injury whose primary representation is the patient perspective on the Committee*.
  - **Caregiver:** A family member or other unpaid caregiver with a significant personal relationship with a patient (as defined above) and who provides a broad range of assistance for the person receiving care and represents this perspective on the Committee**.
  - **Patient and Caregiver Representatives:** Members of advocacy organizations or other organizations that represent patients or caregivers and serve to represent the interests of patients and caregiver interests on the Committee. These representatives may include organizations that represent populations of patients or caregivers and/or patients with certain diseases or conditions.

*Adapted from PCORI definition of Patient https://www.pcori.org/engagement/what-we-mean-engagement/pcoris-stakeholders

**Adapted from the Family Caregiver Alliance definition of Family (Informal) Caregiver https://www.caregiver.org/definition

Increasing Patient Recruitment

New QM Policies on Patient Engagement (continued)

- All CDP, MAP, and relevant Framework Committees to include a minimum of two patient and/or caregivers
  - Aim to accomplish by the conclusion of the nominations period of the fall 2019 cycle.
- 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 will launch in early 2019.

Preparing Patients and Caregivers for Participation in Committees

- NQF CDP Patient and Caregiver Committee Member Mentorship Program
  - Expected to launch a pilot November 2018

Preparing Patients and Caregivers for Participation in Committees

- Facilitation Training on Engaging Patients and Caregivers
  - QM is updating current Facilitation Training sessions to include content on patient engagement.
    - Trainings for committee co-chairs and NQF staff will now include specific content targeted at soliciting the patient voice.

- Patient and Caregiver Friendly Educational Materials
  - QM education team has updated NQF Committee materials to be more patient friendly, clearer, and reduce unnecessary jargon.

Updates on Improving Patient and Caregiver Policies Across QM

Creation of NQF Quality Measurement Patient Advisory Council

- QM is designing a patient engagement council to advise the QM department on matters related to patient engagement. The council is expected to pilot in Spring 2019.

- Council Objectives:
    - 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.
    - Provide feedback on NQF endorsement criteria and process changes.

Updates on Improving Patient and Caregiver Policies Across QM

Creation of NQF Quality Measurement Patient Advisory Council (continued)

- Council activities include:
  - *Quarterly or bi-monthly calls/web-meetings*
  - *Providing feedback on documents*
  - *Participating in outreach to patient groups, organizations, or individuals.*

- The pilot program will initially include 5-6 participants

- The council will be seated via a public Call for Nominations

CSAC Discussion Questions

- Are there any recommendations or additional considerations for current activities?

- Is there still support on the prioritization of activities? Are there initiatives that should be reprioritized?

- What, if any, additional initiatives should NQF consider to better engage patients?