



NATIONAL
QUALITY FORUM

Amplifying the Patient and Caregiver Voice



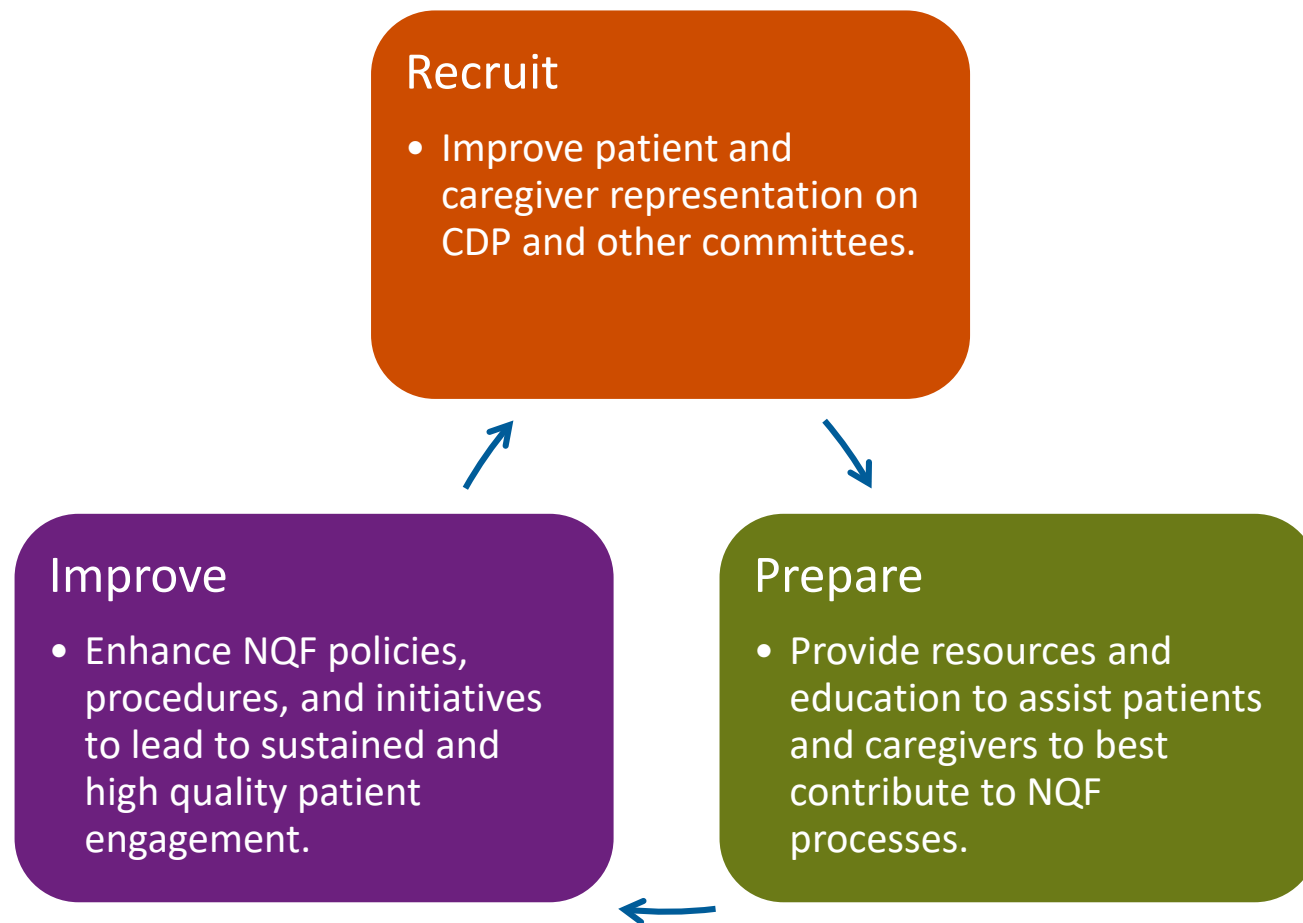
Assessing Best Practices to Capture Patient and Caregiver Voices

- Patient Advisory Group feedback session from patient representatives currently serving on CDP
- Patient and Caregiver feedback from other NQF efforts
- Feedback obtained during NQF annual meeting
- Consumer group calls
- Meeting with Patient-Centered Outcomes Research Institute (PCORI) on best practices for patient engagement activities

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



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

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

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)

CSAC Discussion Questions

- What other mechanisms for recruiting patients to standing committees should be considered?
- Do you agree with the prioritization of these strategies?
- What, if any, additional long-term aspirations should NQF consider to better engage patients?