

NQF Patient & Caregiver Engagement Advisory Group

BACKGROUND

NQF is expanding its efforts to meaningfully engage patients and caregivers in its work with the convening of a newly appointed Patient and Caregiver Engagement Advisory Group. The patient and caregiver voice is vital to the multistakeholder consensus process, to grounding and shaping the landscape of quality measurement, and improving healthcare quality and outcomes. Through this renewed effort, NQF seeks to implement practices, processes, and infrastructure to:

- Mitigate barriers to participation and create a welcoming experience for patients and caregivers collaborating with NQF;
- Prepare patients and caregivers for a successful experience by providing training and support that enables meaningful participation;
- Ground NQF work and outputs in real experiences to ensure that patient and caregiver voices are heard; and
- Foster a convening culture and environment that supports and promotes patient participation.

GROUP CHARGE

The NQF Patient and Caregiver Engagement Advisory Group will provide strategic input and direction on engaging patients and caregivers in shaping NQF processes, programs, products and deliverables. This group will advise NQF on matters related to recruitment, education, and retention of patient/caregiver representatives in NQF's Consensus Development Process (CDP), Measure Applications Partnership (MAP), and measurement science projects.

Specifically, the group will be charged with the following activities:

- Provide input and feedback on strategies to recruit patients onto NQF committees.
- Assist in recruitment and retention activities.
- Provide strategic direction 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.

GROUP STRUCTURE

The group will be comprised of 5-7 individuals. Participation will include quarterly or bi-monthly calls/web-meetings, of approximately 1-2 hours duration. Group members may also be asked to assist with additional work, such as providing feedback on documents or participating in outreach to patient groups, organizations, or individuals. Monthly time commitment is expected to be 1-2 hours or less. Ongoing participation of individual members will be evaluated on an annual basis.

PREFERRED EXPERIENCE

NQF is seeking Patient and Caregiver Engagement Advisory Group members with prior experience serving as a patient, caregiver, or patient/caregiver representative on an NQF committee, panel or group. Applicants should be committed to patient engagement in healthcare quality issues and sharing experience and knowledge to support NQF efforts to engage patients in our work.

NQF defines patient and caregivers as the following:

- 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 Committee¹.
- 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 Committee².
- 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.

APPLICATION REQUIREMENTS

Nominations are sought for individuals/organizations and individual subject matter experts. Self-nominations are welcome. Third-party nominations must indicate that the individual or organization has been contacted and is willing to serve.

Nominees must be available on <u>April 24, 3:00-4:30pm ET</u> for the initial Patient and Caregiver Engagement Advisory Group Orientation Conference Call. Future meeting dates will be decided based on the group's availability.

To nominate an individual to the Patient and Caregiver Engagement Advisory Group please **submit** the following information:

- a completed online nomination form, including:
 - a brief statement of interest, including a description of the nominee's experience with NQF programs and activities
 - o a short biography (maximum 100 words), highlighting experience, knowledge and prior related activities
 - o curriculum vitae or list of relevant experience

DEADLINE FOR SUBMISSION

All nominations *MUST* be submitted by **6:00 pm ET on April 1, 2019.**

QUESTIONS

¹ Adapted from PCORI definition of Patient https://www.pcori.org/engagement/what-we-mean-engagement/pcoris-stakeholders

² Adapted from the Family Caregiver Alliance definition of Family (Informal) Caregiver https://www.caregiver.org/definitions-0

If you have any questions, please contact Kate McQueston at 202-783-1300 or patients@qualityforum.org. Thank you for your interest.