



Patient Safety Standing Committee Proposed Roster with Public Comments and NQF Responses

Patient Safety Standing Committee Proposed Roster – Public Comments

Name of Commenter:	Organization Affiliated:	Comment:	Comment Received:
Christian John Lillis	Peggy Lillis Foundation	<p data-bbox="756 568 1554 646">Dear Friends,</p> <p data-bbox="756 649 1554 828">I was troubled to learn that NQF's new roster for its Patient Safety Committee represents a net loss of 1 patient advocate. The standing committee currently has 3 patient advocates out of 30 total members.</p> <p data-bbox="756 831 1554 1299">It strikes me as counter to the mission, goals and perception of a patient safety committee to have less than 10% of its members be patient advocates. This is not to suggest that the other 27 members, several of whom I know and have worked with, are not well-meaning and good faith representatives of their organizations and professions. Nor does it erase that they, too, receive medical care and, in that sense, are patients. What it does mean is that they do not enter into these discussions SOLELY to represent patients, particularly those who have been harmed or killed through interactions with our healthcare system.</p> <p data-bbox="756 1302 1554 1408">I was drafted into the work of patient safety by the preventable and unnecessary death of my mother, Peggy, from a C. difficile</p>	December 17, 2020

infection that was allowed to escalate due to the negligence of her dentist and primary care doctor. As you may know, I participated in the Task Force that developed NQF's Antibiotic Stewardship Playbook, presented at your annual conference, and, most recently, participated in an incubator meeting about developing measures for community-acquired C. diff.

The organization I lead, Peggy Lillis Foundation for C. diff Education & Advocacy, represents over 1,000 C. diff patients and survivors as well as over 500 family members. Our sole focus is improving the healthcare system and the policies that allow 500,000 people to be infected by a preventable disease and upwards of 30,000 dying.

For NQF to seriously engage with the perspective of patients, particularly those who have receive sub-par, low quality and, too often, dangerous care, you need to include advocates whose sole focus is to represent patients.

I believe NQF does important work. Work that PLF is happy to support. However, we think that work would be greatly improved by MORE patient advocates.

I look forward to hearing from you and seeing that NQF keeps its commitment to engaging greater numbers of patient advocates.

Response:

Thank you for the comments. We recognize the importance of patient/consumer input and participation within our consensus development work, and we strive to achieve balanced

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representation within NQF Standing Committees. We have maintained a consistent representation of patients/consumers on the Patient Standing Committee and look forward to continuing to do so in future years.

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Carol Cronin	Informed Patient Institute	To Whom It May Concern,	December 17, 2020
Patricia Kelmar, JD	NQF Patient and Caregiver Engagement Advisory Committee	<p>We would like to express our strong concern about the proposed roster of new members to the NQF Patient Safety Committee that was made available for public comment on 12/4/20.</p> <p>The proposed roster of new members includes nine representatives from the provider community, one representing the employer perspective and none from the patient/consumer community. This despite the fact that we know of at least one highly qualified patient advocate who we recruited to apply. And there were probably others as well. Because the NQF Patient Safety Committee has lost the input from a highly experienced patient advocate, Lisa McGiffert who was termed out of the committee, the balance of voices on one of the most important committees deciding on safety measures affecting all patients is going in the opposite direction regarding the patient/caregiver view. With only two patient voices left on a committee of at least 26 members, the end result is clearly not close to being representative of the importance of the</p>	

patient/caregiver perspective when evaluating quality measures that will impact care received in future years.

We were particularly disappointed given our volunteer work over the last year on the NQF Patient and Caregiver Engagement Advisory Committee whose goal is to help identify and recruit qualified patient/caregiver applicants. We put significant time and effort to improve NQF's recruitment efforts in this important community. And the end result may be a net loss for patient voices. As acknowledged by NQF staff working with the Advisory Committee, this is not an easy process for patient/caregiver applicants who are volunteers and don't have the organizational support structures and processes to both apply and then conduct this work. It is disappointing and counter to the expressed goals of NQF and its funder, CMS to end up being less inclusive of the patient voice.

We have not yet evaluated whether and how this same outcome affected other NQF committees seeking new applicants but would hope no other committees experienced a LOSS of patient/family/consumer participation as a result of this most recent selection process.

We strongly urge NQF to reconsider this proposed roster, review other qualified applicants from this and previous cycles of nominations, and add another patient/family/consumer representative to the NQF Patient Safety Committee.

		<p>Response:</p> <p>Thank you for the comments. We recognize the importance of patient/consumer input and participation within our consensus development work, and we strive to achieve balanced representation within NQF Standing Committees. We have maintained a consistent representation of patients/consumers on the Patient Standing Committee and look forward to continuing to do so in future years.</p>	<p>Response Sent:</p> <p>December 21, 2020</p>
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Melissa Clarkson Helen Haskell Lisa McGiffert Yanling Yu	Patient Safety Action Network Leadership Committee	<p>We are writing our concern regarding appointments for the Fall 2020 cycle of the National Quality Forum's Patient Safety Committee. Our comments today are in response to the proposed roster for the new members of the Committee made available for public comment on December 4th.</p> <p>The Patient Safety Action Network began to develop in 2015. After nearly 15 years of collaboration with the Consumer Reports Safe Patient Project, which ended in 2018, advocates from across the US decided to continue our work to end medical harm. Our members, including individuals and organizations, are specifically engaged in advocating for improved safety that will end medical harm.</p>	<p>December 17, 2020</p>

We support the development and public disclosure of patient safety measures that are considered by this NQF Committee. Several of our members have served on this committee. We believe they significantly contribute to the discussions for endorsing outcome measures for improving safety that are meaningful to patients and caregivers. Most of our members are interested in improving safety across the health care spectrum and many of them have gained significant experience in similar committee work by serving on CMS-sponsored Technical Expert Panels, state-based infection prevention advisory committees, state boards overseeing physicians and nurses, federal agency advisory panels (e.g., FDA, CDC, AHRQ), as well as other stakeholder groups interested in safety issues. Bringing seasoned advocates' voices to these tables is a major goal of our work.

We are aware that NQF has in recent years stated a desire to help identify and recruit qualified patient/caregiver applicants for its committees and that NQF even organized a Patient and Caregiver Engagement Advisory Committee to assist in meeting those goals. However, despite these efforts, we are very disappointed that the proposed roster for the Patient Safety Committee will actually diminish the consumer/patient voices that were present in the last several cycles.

That roster includes nine health care providers representing that community and one person representing the employer community seeking quality information when choosing health plans for their employees. No people representing the patient/consumer community were selected, even though

several very qualified advocates applied in an effort to replace a long-time member of the committee with a strong consumer voice who was termed out.

We strongly urge NQF to reconsider this proposed roster, review other qualified applicants from this and previous cycles of nominations, and add another patient/family/consumer representative to the NQF Patient Safety Committee.

Response:

Thank you for the comments. We recognize the importance of patient/consumer input and participation within our consensus development work, and we strive to achieve balanced representation within NQF Standing Committees. We have maintained a consistent representation of patients/consumers on the Patient Standing Committee and look forward to continuing to do so in future years.

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