Palliative and End-of-Life Care Standing Committee Proposed Roster with Public Comments and NQF Responses

Palliative and End-of-Life Care Standing Committee Proposed Roster –Public Comments			
Name of Commenter: **Craig Jeffries** **Vice President, Public Policy**	Organization Affiliated: Compassus	Comment: We fully support the roster as presented.	Comment Received: 3.8.2016
		Response: Thank you for your response and support.	Response Sent: 3.25.2016
Name of Commenter: **Jennifer Lundblad PhD, MBA** **President & CEO**	Organization Affiliated: Stratis Health	Comment: Thank you for the opportunity to comment on the proposed roster for the Palliative and End-of-Life Care Committee. We enthusiastically support NQF's focus on these areas, and are impressed with the roster of committee members you have selected. However, we want to encourage you to consider whether you had adequate rural perspective and expertise among the group. People in rural communities have less access to palliative and end-of-life care services, but potentially greater need. To date, the majority of palliative care programs have developed primarily in large hospitals in urban settings, and delivery models for palliative care for rural communities lag behind. However, rural populations are disproportionately ill, disabled, poor, and older. Rural adults are also more likely than their urban counterparts to have a range of chronic conditions. For these reasons, we believe it is essential that the NQF committee include enough rural perspective and expertise to make meaningful contributions to the efforts of the committee. While we do not know all of the proposed committee members, we do know that a few of them have some exposure to rural health care – notably, Drs Ritchie, Moss and Vanderkieff all live in places with rural communities. What we don't know is whether they will be invited or expected to bring the rural voice to the committee work. Stratis Health is a non-profit quality improvement organization based in Minnesota. Rural health, palliative care, and end-of-life care are organizational priorities for us. We have extensive experience working with rural communities, clinicians, and health care organizations to build their capacity to offer palliative care, hospice, and advance care planning. We rely on the NQF for measures which provide us the basis for designing our improvement interventions and assessing	Comment Received: 3.11.2016

		results. For example, we recently completed a rural palliative care pilot measures study to identify and field test a standard set of quality measures for rural, community-based palliative care programs, which used NQF measures. The study was published in May 2015 in the Journal of Palliative Medicine (http://online.liebertpub.com/doi/abs/10.1089/JPM.2014.0435?journalCode=jpm). We encourage you to either clarify with proposed committee members their willingness and ability to represent rural interests on the Committee, or to review and re-consider others who applied who would specifically be able to offer rural expertise and insight on the Committee. Thank you for your time and attention, and we are eager to follow the work of the committee.	
		Response: Thank you for your comment. NQF recognizes the importance of the rural perspective in measurement issues. While the selected Standing Committee members may not actually reside in rural or frontier areas, many understand the issues regarding unequal access to palliative care, particularly for those who live in rural areas. Members will be encouraged to share their knowledge and expertise in this area with the full Committee.	Response Sent: 3.25.2016
Name of Commenter: jimlomastro@comcast.net	Organization Affiliated:	Comment: I do not have any issue with the qualifications of the members with the exception is the group does not seem to have any non-academics and non-providers. (At least as far as I can see and I am be mistaken) Given that the Triple Aim as well as current literature in the "patient experience" and the role of the "patient" not just in their care but also providing their perspective to healthcare. In the non-healthcare social sector, there are many boards, groups, committees and the like that have many non-provider, non-system people in some cases in the majority of the members. I do understand that many areas require some understanding of "technical" aspects. Beside that "disadvantage" outweighed by the alternative, non-vested perspective that they bring, there are many non-providers who through prior work or involvement have technical experience. I have worked for eight years on a particular Patient and Family Advisory Board and a statewide one and found that providers felt that they added value not only from their experience but also that there was not a vested interest or a professional perspective to hinder seeing the issue or problem differently.	Comment Received: 3.15.2016

	Bakan quoting Riesman indicated that the people who were qualified to be creative and objective about the contemporary world situation are amateurs (non-professional thinkers who practice). The reason is the experts have vested interests in the status quo and amateurs will possibly succeed where experts will not. Unfortunately, we have left much of thinking about how to deal with the human problems of contemporary society, and consequently, how we practice to professional thinkers, who are disconnected from the practice and fail to see the consequences of their thinking. The insights of practitioners (amateurs) will hopefully provide breakthroughs on how we think about issues and make progress. In this effort amateur, as we will relate is inexperienced, uninitiated or non-professional as much as the root meaning of the word indicates – grounded, passionate and committed.	
	Response: Thank you for your comment. NQF recognizes the importance of selecting Standing Committee members who bring a diversity of perspectives to the table, including the patient and consumer voice. We are very pleased that two of the selected Standing Committee members—Amy Berman and Laura Porter—will bring a first-hand patient perspective to the deliberations. Both are stage-4 cancer survivors who are committed to improving the quality of care and the experience of care for those with chronic and/or terminal conditions. While both individuals are clinicians, each was selected for the Palliative and End-Of-Life Care Standing Committee specifically because of their experience as patients, not as providers.	Response Sent: 3.25.2016