December 11, 2017

Shantanu Agrawal, MD, MPhil
President and CEO
Elisa Munthali
Acting Senior Vice President, Quality Measurement
National Quality Forum
1030 15th Street NW
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Washington DC 20005

RE: NQF Measure 0138 and patients with Spinal Cord Injury

Dear Dr. Agrawal and Ms. Munthali:

On behalf of the undersigned interdisciplinary organizations representing individuals with spinal cord injuries (SCI) and the professionals (physicians, researchers, nurses, therapists and mental health professionals) who care for them, we are requesting that the NQF conduct a review of the risks and benefits of Quality Measure 0138 for SCI patients and consider downgrading it to conditional endorsement status.

In the spring of 2014, care providers of patients with SCI reported a surge in unsafe bladder management practices soon after the transition toward "Pay for Performance" status of the National Healthcare Safety Network (NHSN) Catheter-associated Urinary Tract Infection (CAUTI) Outcome Measure. These practices include indiscriminate removal of Foley catheters in non-specialty hospitals, with little understanding of the importance of intermittent catheterization volumes, patient independence, bladder compliance, and overflow incontinence in SCI patients. This incomplete understanding has led to undiagnosed Autonomic Dysreflexia (AD) and UTIs related to bladder overdistension and retained urine. Bladder overdistension is the leading cause of AD,[1] which leads to hypertensive emergency and potentially life-threatening consequences. Understanding of the recognition and treatment of AD has been shown to be quite limited among non-specialty healthcare providers,[2,3,4] and we have data from a Level I trauma center demonstrating 57% of intermittent catheterization volumes exceeding the maximum recommended by published guidelines. These patients demonstrated blood pressures consistent with AD.

SCI providers also raised concerns about the validity of this measure's definition of UTI for these patients. The NHSN definition of UTI includes symptoms of suprapubic tenderness, flank pain, and fever. SCI patients typically have impaired sensation in the suprapubic and flank areas, and thermoregulation is altered in this patient group.[5] Hence, we have reason to believe that the benefits of this particular type of surveillance have been overestimated for SCI, as demonstrated by a poor sensitivity (42%) and a high false-positive rate (58%) for the NHSN definition of UTI in SCI patients seen in data from an SCI center. This unpublished data corroborates the findings of previous published work.[6,7]

It is well established that the duration of indwelling catheterization is directly related to risk for developing UTI. Therefore, expeditious Foley removal is a mainstay of CAUTI prevention,[8,9] and is one of the most evidence-based strategies hospitals can use to reduce their CAUTI Standardized Infection Ratio. Since Quality Measure 0138 is included in Medicare's Quality Reporting and Value-Based Purchasing programs, and is subject to public reporting through Medicare's Hospital Compare website, non-specialty hospitals now have financial and public reporting incentives to remove Foleys and assume care over neurogenic bladder in SCI – a competency which is not widely taught outside of SCI centers.

Soon after we raised our concerns in 2014, the NQF connected us with the measure developers, for which we are grateful. We arranged for two separate informal phone conferences between the measure developers and some highly-respected members of the SCI academic community. These discussions did not occur with NQF oversight, and we did not reach any mutually satisfactory conclusions. To our knowledge, no minutes were taken at these meetings. Furthermore, subsequent Measure Summaries submitted to the NQF by the measure developers contained no mention of our concerns in section 4c – the section concerning "unintended consequences to individuals or populations." This informal process lacked the organized structure, transparency, and accountability that is characteristic of the NQF.

When SCI providers approached the Joint Commission with similar concerns regarding their CAUTI National Patient Safety Goal (NPSG), the Joint Commission assigned two people to conduct an investigation, meet with SCI experts, and produce a written report. The findings of this investigation culminated in changes to the CAUTI NPSG that acknowledge these safety concerns and recognize the important role that indwelling catheters play in safely managing SCI neurogenic bladder.

Despite the changes to the CAUTI NPSG that took effect last January, the problems our members are seeing in acute care hospitals continue unabated, and financial incentives remain unchanged. We believe this issue is worth revisiting – this time with data that has been collected from SCI centers. This time, however, we are requesting the direct oversight and wisdom of the NQF, along with its characteristic organization, transparency, and accountability.

We hope that you agree that this situation merits a more structured approach. We are open to any intervention that addresses our concerns about patient safety, that conforms with Clinical Practice Guidelines regarding selection of bladder management method,[10] and that has a reasonable chance of success. This could include the development of an alternative quality measure that more specifically addresses quality of care in bladder management in SCI. If you have further questions or wish to reply to this letter, please feel free to reach out to Dr. Matthew Davis, who serves as the chair of the advocacy committees of ASIA and ASCIP and who has been involved in this issue from the beginning.

Sincerely,

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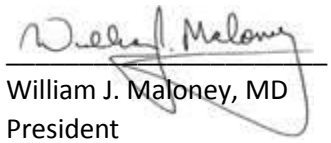

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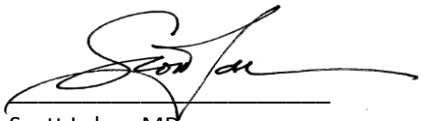

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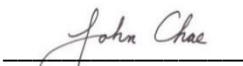

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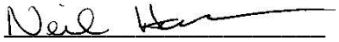

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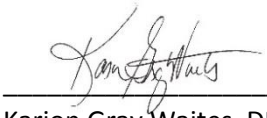

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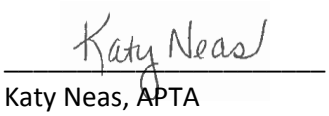

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