Nomination for PCORI Board of Governors

I nominate myself, Danny van Leeuwen, as a patient/caregiver stakeholder for the PCORI Board of Governors. As a person with disabilities from Multiple Sclerosis, a caregiver for my grandmother, mother, and son’s end-of-life journeys, a registered nurse for 42 years, an informaticist, and a quality management professional, I bring broad and deep experience to this vital government service.

My experience with PCORI began in 2012 when I was invited to Washington, DC, to a roundtable of stakeholders. I began reviewing funding requests in 2013. With my broad professional and personal experience in Home Care, Physical and Cognitive Disabilities, Emergency and Intensive Care, Behavioral Health, Palliative Care, and Managed Care, I have been invited to review Improving Health Systems, Palliative Care, Reducing Opioid Use, and Pragmatic Studies applications. I co-chaired PCORI’s Communication and Dissemination Research Advisory Panel for three years and now co-chair the new Clinical Effectiveness and Decision Science (CEDS) Advisory Panel. I spoke about my experience with PCORI at the 2017 PCORI Annual Meeting.

Currently as a patient/caregiver stakeholder, I serve on CMS-funded Supporting Efficiency and Innovation in the Process of Developing CMS Quality Measures Technical Expert Panel. I’m on the Steering Committee of the AHRQ-supported Patient-Centered Clinical Decision Support (PCCDS) Learning Network. I was appointed as a technical expert to the Governor’s MassHealth Payment and Care Delivery Reform Quality Improvement Work Group.

I belong to the Society of Participatory Medicine and edit its Newsletter. I was on the faculty of the Leadership Academy of the Organization of Nurse Leaders of MA, RI, CT, and NH from 21012-2018. I belong to the Northeast Health Information Management Systems Society (HIMMS), the Academy of Communication in Healthcare (ACH), and the National Association of Healthcare Quality. I was an inaugural member of HIMSS national Connected Patient Committee and served on their Safety, Cost, and Quality Committee.

I am a prolific author. My original research, Are medication error rates useful as comparative measures of organizational performance? was published in the *Joint Commission Journal on Quality Improvements*. The *British Medical Journal* recently published an article of mine, as did the *Journal of Participatory Medicine*, Communication at Transitions, One Audacious Bite at a Time. I served 15 years as an editor of the *Journal for Healthcare Quality* and am currently on the Editorial Review Board for the *Journal of Participatory Medicine.* I have been blogging weekly for six years as a patient/caregiver activist and am regularly asked for guest posts about patient/clinician relationship, research, and technology. I have been invited to speak regularly about patient engagement, technology, and leadership: Beryl Institute’s Patient Experience Conference, Medical Group Management Association (MGMA), Medical Informatics World Conference, HIMSS, ANCC National Magnet Conference, and others.

I delight in the opportunities I’ve had with PCORI as its mission and my mission align so well. I’m committed value my ability to contribute to this example of good government at work. Please appoint me to this position on the PCORI Board of Governors.