1. **Patients or caregivers with experience relevant to the conference’s central theme actively participate in the design and planning of the event, including the selection of themes, topics and speakers.**

   The [PCORI Annual Meeting](http://www.pcorian.org) has been led by a steering committee comprised of multiple stakeholders from the healthcare landscape including patients and caregivers. The committee charter is [here](http://www.pcorian.org). The charter outlines their responsibilities and notably indicates that the steering committee shall, “provide input on meeting goals, target audiences, themes, topics, speakers, types of presentations, and success metrics.”

   Stephanie Buxhoeveden, MSCN, MSN, FNP-BC, Danny van Leeuwen, MPH, RN, CPHQ, and David White have served as the patient representatives on the committee.

   **Stephanie Buxhoeveden**, MSCN, MSN, FNP-BC, Neurology Associates of Fredericksburg

   Stephanie Buxhoeveden was diagnosed with multiple sclerosis (MS) at the age of 25. She was in graduate school and working as a neurosurgical ICU nurse at the time, and shortly after her diagnosis she realized she could use her experiences as a patient to have a positive impact on the MS community. She now works as a nurse practitioner and specializes in the care of people living with MS and other complex neurological conditions. Buxhoeveden also writes for several publications and is involved with organizations including iConquerMS, the National MS Society, and Can Do MS. As an MS activist and District Activist Leader, she works tirelessly to increase MS awareness, lobby for research funding, and advocate for important legislation at the State and national levels. She earned her certification as an MS Certified Nurse and graduated summa cum laude with her master’s degree in the science of nursing from Rutgers University.

   **Danny van Leeuwen**, MPH, RN, CPHQ, Advisory Panel Member, Advisory Panel on Communication and Dissemination Research (co-chair), Vice President, Quality Management, Advocates, Inc.

   Danny van Leeuwen, MPH, RN, CPHQ, a nationally recognized nurse leader and advocate for family caregivers, is an ePatient with multiple sclerosis, a caregiver, a nurse, and a leader. He has led the Patient Family Experience initiative for Boston Children’s Hospital, serves on the HIMSS Connected Patients Committee, and is a member of the Society for Participatory Medicine. He speaks nationally about family caregivers and health information technology and hosts a weekly blog ([http://www.health-hats.com](http://www.health-hats.com)) with more than 2,000 registered users. His career includes experience as a nurse, QI director, health informatics specialist, author, and researcher. He attained national recognition for his published works in the Joint Commission Journal on Quality Safety and the Journal for Healthcare Quality, where he was an editor for 15 years.

   **David White**, Volunteer, Advisory Panel Member, Advisory Panel on Patient Engagement

   David White is a veteran of in-center, in-center nocturnal, and peritoneal dialysis, and received a kidney transplant in 2015. Before his kidneys failed, White was an information technology manager for an international law firm.

   He currently serves as Chair of the Kidney Health Initiative's Patient and Family Partnership Council. He also serves on the American Association of Kidney Patients Board of Directors and the Veterans Transplantation
Association Board of Directors. He enjoys speaking about kidney disease awareness and patient engagement, and has made regional and national television appearances as a patient advocate. White has a BS in mathematical studies from Yale University and is pursuing a degree in health systems management from the University of Maryland University College.

2. Patients or caregivers with experience of the issues addressed by the event participate [2] in its delivery, and appear in its physical audience.

   The Annual Meeting program includes plenary and breakout sessions where patients have been actively involved in the planning, development, and delivery, as well. The opening plenary session entitled, “Access to Results That Matter” is a patient-centered topic. The keynote will be delivered by Freddie White-Johnson, founder and president of the Fannie Lou Hamer Cancer Foundation, an organization that is committed to preventing cancer in the Mississippi Delta by increasing awareness and establishing a public agenda for the prevention of cancer. The session is then followed with a panel discussion with other patients, and representatives from the caregiving and patient navigator/community health workers. The three other plenary sessions which were developed by the steering committee will focus on patient-centered themes, and include discussion panel with patient representatives. The topics are:

   - Communicating Science and Healthcare Research to the Public
   - Making Shared Decision Making a Standard Practice in Health Care
   - How CER/PCOR Can Support a Patient-Centered Healthcare System That Provides Value for All

   The breakout sessions focus on PCORI funded research studies. Each research team and project presented is required to include a presentation with the principal investigator and patient project partners. The travel, hotel, registration, and incidental costs for the presenters are covered by PCORI.

   Patients and caregivers represent the second largest group of participants in the meeting after researchers.

3. Travel and accommodation expenses for patients or careers participating in the advertised program are paid in full, in advance. Scholarships [3] are provided by the conference organizers to allow patients or careers affected by the relevant issues to attend as delegates.

   Since the first PCORI Annual Meeting in 2015, PCORI is pleased to offer a limited number of scholarships for individual patients and caregivers, as well as representatives from patient and caregiver organizations to attend our 2017 Annual Meeting. Scholarships will cover the costs of travel, hotel, registration, as well as an allowance for transportation, baggage costs, and meals not provided during the meeting. Scholarships will cover both applicants and a caregiver if medically necessary. Applicants are asked to submit statements of interest and need, and priority will be given to patients and caregivers who did not receive a scholarship to attend last year’s meeting. Additionally, current involvement with PCORI is not a requirement and scholarships for patient/caregiver organizations will be limited to one per organization. Applications are reviewed by the PCORI Patient and Stakeholder Engagement staff. The reviewers will look for patients and caregivers with a strong interest in patient-centered outcomes research and comparative clinical effectiveness research. The scholarship program information is available here. The deadline to apply for a scholarship was July 21, 2017 and all scholarship award notifications were announced on August 10, 2017.

   All travel and accommodations for patients and caregivers participating at the PCORI Annual Meeting are paid in full by PCORI. Patients and caregivers invited to speak or who are scholarship recipients are provided with direct access to the PCORI travel agency where they book travel and to ensure all upfront costs are billed directly to us. Additionally, the patients and caregivers are provided with a stipend upon arrival to provide funds for expenses not covered by PCORI during the event such as taxi, tolls, mileage to and from the airport, meals, and incidentals.

4. The disability requirements of participants are accommodated [4]. All applicable sessions, breakouts,
ancillary meetings, and other program elements are open to patient delegates. PCORI provides full support for participants with disability requirements. During the registration process, we capture requirements and work with the participant and the host venue to satisfy the accommodations. The Crystal Gateway Marriott also provides ADA compliant rooms as applicable. We ask all meeting registrants if they need to travel with a caregiver. In response, PCORI provides travel and accommodations for caregivers without question.

5. **Access for virtual participants is facilitated, [5] with free streaming video provided online wherever possible.** Webcasts, including 4 plenary sessions, 8 breakout sessions with 2 special sessions covering MS and Opioids, will be available through free streaming video online. These webcasts sessions highlight the impact of patient-centered outcomes research. These multimedia events offer the public with access to the PCORI 2017 Annual Meeting at no cost. The sessions include:
   - Improving Healthcare Efficiency
   - Why Methods Matter: Putting Research to Work for Individual Patients
   - Patient-Centered Strategies to Improve Health and Health Outcomes for Vulnerable Populations
   - Addressing the Opioid Crisis by Improving Pain Management

Registration to the webcasts is available [here](#) once registration opens.

**Additional Information:**
The Patient-Centered Outcomes Research Institute is committed to patients. This is reflected in our vision:

Vision Patients and the public have information they can use to make decisions that reflect their desired health outcomes.

And our mission:

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.