



**2016 PCORI Annual Meeting
PATIENTS INCLUDED REQUIREMENTS**

- 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](#) has been led by a steering committee comprised of multiple stakeholders from the healthcare landscape including patients and caregivers. The committee charter is [here](#). 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.”

Terry Summerlin, MA and Danny van Leeuwen, MPH, RN, CPHQ have served as the patient representatives on the committee.

[Terry Summerlin](#), MA, Volunteer, Arthritis Foundation

Terry Summerlin, MA, has been a volunteer with the Arthritis Foundation for over 25 years, serving on local and state boards and advocating for patients locally and in DC. She has taught medical students how to perform a musculoskeletal exam at UTHSC for the past 20 years. Summerlin was an original Patient Partner, and she helped edit training manuals and train others. She has given presentations all across the United States and in London, England. As a patient, she has had over 20 operations on her joints. Summerlin is also part of the PCORI Ambassador Program. She has a BS and MA in psychology.

[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>) 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.

- 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, “How can we make patients’ needs and values central to health research and decision making?” is a patient-centered topic. The keynote will be delivered by Ronnie Sharpe, a patient, and founder of CysticLife, an organization that works to positively impact the lives of the cystic fibrosis (CF) community by creating educational materials and empowering patient-driven research, and through its social network, CysticLife.org. 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:

- Taking Stock: How is Patient-Centered Outcomes Research Advancing Patient-Centered Care?
- How Can PCOR/CER Improve Care for People with Multiple Chronic Conditions?
- A New Vision for Health Research: Finding Common Ground Among Stakeholders

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 carers participating in the advertised programme are paid in full, in advance. Scholarships[3] are provided by the conference organisers to allow patients or carers 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 2016 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 September 30, 2016 and all scholarship award notifications were announced on October 12, 2016.

All travel and accommodations for patients and caregivers participating 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 programme 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 Gaylord National Resort & Convention Center 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 and Facebook Live Session are available through free streaming video online. These webcasts sessions highlight the impact of patient-centered outcomes research and the Facebook Live session focuses on smarter use of antibiotics. These multimedia events offer the public with access the PCORI 2016 Annual Meeting at no cost. The sessions include:

- How can we make patients' needs and values central to health research and decision making?
- Taking Stock: How is Patient-Centered Outcomes Research Advancing Patient-Centered Care?
- How Can PCOR/CER Improve Care for People with Multiple Chronic Conditions?
- A New Vision for Health Research: Finding Common Ground Among Stakeholders

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

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.