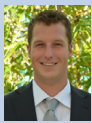


## Patients and Researchers Can Go Further, Together



### Stephen Hoy

Stephen Hoy is the Chief Operating Officer at PFCCpartners. Diagnosed with mitochondrial disease as a child, Stephen has extensive experience in managing his health to best support an active lifestyle of outdoor activity. Growing up so deeply involved in his own care has given Stephen a profound view of how patients and families can be utilized as a resource across the healthcare continuum. He now serves as a Patient Family Advisor locally at Mammoth Hospital in California, and nationally in partnership with organizations like National Quality Forum (NQF), Centers for Medicare and Medicaid Services (CMS), Institute for Healthcare Improvement (IHI), and the American Institute of Research (AIR).

This Viewpoint was prepared in response to the discussion held at a Robert Wood Johnson Foundation and AcademyHealth meeting on Patient Centered Care that took place in May 2019. This invitational meeting was attended by experts representing patient, provider, payer, policy, and research stakeholders' perspectives, and the meeting was informed by a [discussion paper](#) prepared by researchers at the Harvard School of Public Health on the barriers to delivering patient centered care.

“You are an expert in your experience, and that is what you are there to provide.” Since the day I was given this advice, I have carried it in my pocket for when I start to wonder, “why I am in this room?” The feeling only lasts a moment, then I realize finally, we are all working on the same thing—making the system better, making care better, so everyone can have the health they desire.

### Why am I here?

I feel like I was born for this role at times. My journey started as a child, sharing the burden of mitochondrial disease with my two younger brothers. Diagnosed at a young age, we grew up very familiar with hospitals, emergency rooms, clinics, and labs. It wasn't until I was older that I recognized most of my friends were not as accustomed to their everyday life being woven in with the health system. They were not as accustomed to an ambulance parked in the driveway. Or finding unplanned babysitters in the morning because little brother was back in the ED. I remember being woken up in the middle of the night to ambulance lights in the driveway. I would roll over and go back to bed—intent on waking up and going to school the next day. It was in fact, just another day in the life.

Fortunately, we had a tremendous support system that stood on the shoulders of a heroic mother who worked tirelessly so we could experience life as all children should. Because of her and the team she quarterbacked around us, being fed through tubes, having spines fused, and surviving those hypocritical hospital-acquired infections has left us no harm. Only a lengthy resume of experiences that have made me an expert in one thing—getting what I needed out of our complex health care system. Without this level of engagement there is no way I could have gone skiing with a PICC line or continued on the local surfing team with a back brace. These are the experiences that make me an effective patient and family Advisor.

## Patient Advisors: Partners for Co-Design

Tireless efforts from tremendous individuals have shined a light on the glaring gap in patient centeredness in our health system. The opportunity for partnership as an advisor would not be there if not for the work of our advocates in the past few decades. I see my work as an “Advisor” as a slightly different function than that of the more visible “Advocate”. Advocates have this clear goal in mind—to shine light or bring awareness to an issue. As an advisor, I do not come with a goal in mind. I make myself available as a partner for the co-design of solutions. I am an expert in my journey, and that is what I bring to the partnership. A voice of balance and sense-making that keeps the most important stakeholder at the center of improvements.

I have taken a few less trips around the sun than some of my colleagues, and entered an environment that has realized something is wrong. One that is beginning its journey and has already started to value the perspective I bring. I can only thank the advocates and advisors before me that have created this space. A space where someone like me can find himself convened by the Robert Wood Johnson Foundation (RWJF) in Washington D.C. to work alongside national experts on the delivery of patient centered care.

As with many new endeavors in this work, the way in which I am going to contribute is not always clear ahead of time. And like many advisors, I accept the challenge with enthusiasm and hope that I can bring at least one contribution. My anxiety about being able to contribute was quickly calmed when I started reviewing the discussion paper prepared for the RWJF meeting: Barriers to Delivery of Patient Centered Care in the U.S. Health Care System. I could tell I would be walking into a room that shared my purpose and vision but spoke differently about it. That is my favorite kind of room to be in.

## What is patient centered care? Evidence and experience align.

My immediate reaction to the discussion paper was, “Wow, I did not know there were 113 references that could be made about Patient Centered Care.” For the longest time, the evidence for patient centered care was almost non-existent. I even used to get frustrated with the question, “where is the evidence?” My advisor peers all passionately move this model forward without any peer-reviewed scientifically acceptable evidence base. But we all need our own evidence to be passionate about patient centered care. Fortunately, every day that I am back skiing mountains or surfing the California coastline is my evidence base for why patient centered care should be available to everyone. Researchers do not have this luxury, nor would my evidence speak to them. So, I am thrilled to see our research community starting to drink the Kool-Aid.

The historical lack of academic attention is what made me nervous about building a definition of patient centered care from a literature review. But quickly, I realized we really were talking about the same thing. I could see important elements of my life reflected in the Patient Dashboard and Domains presented in the discussion paper. Access—I use a menu of services and specialists that needs to be coordinated. Care Preferences—I require and am ready for a high level of shared-decision making. Goals—I’m sure they are clear by now. It is these parts of my life that the health care system would need to understand in order to deliver patient centered care.

## Patient Centered Care: What’s missing?

The need for a system of health care delivery that considers these domains was all too familiar. I’ve watched the most well intentioned and caring providers have their hands tied behind their backs by the system that does not integrate these domains. For example, we asked for a list of medications to start getting grandma ready to go home, and the nurse had to “accidentally” leave the screen open on the computer while she took a fake bathroom break. All because the hospital’s policy is to release medication lists only upon discharge.

So patient centered care sounds great to everyone, why aren’t we there yet? We recognize there is missing information that is needed about each person, how do we collect it? We see a glaring lack of trust and mutual respect. We all feel the negative effects of a culture that does not adequately value patient context. Then there is the glaring barrier that delivering patient centered care is not a sustainable business model in today’s industry.

With this constellation of barriers, the task of delivering patient centered care seems overwhelming. We will never get the information we need without trust. We can never hope to change culture without changing the incentives that built that culture. What excited me most about the recent RWJF meeting is the level to which our research communities are joining in the journey. These are some of the smartest people who can create and share knowledge for true change. And there is a growing ocean of patients and families who wish to support these efforts as true partners in this work. It is no secret that research efforts value being efficient in their approach. But I think when we start to invite patients and families into that process, we will see research that is more effective.

We are all working toward the same thing, and we all bring our own expertise. There will not be a single person who has all of the answers. Co-design and collaboration will make research more effective. Consider new ways to get a pulse on the realities of research topics, even if a Request for Proposals does not require it. If we wanted to go fast, we would go alone. Let’s stop going so fast and go together so that we can ALL go further.