**EPISODE EIGHT:**
Re-engineering Precision Medicine: a Patient Perspective on the Gap Between Innovation and Application

Brad Power, Patient Advocate and Journalist | February 26, 2019*Welcome to* [*The Precision Medicine Podcast*](https://www.interventioninsights.com/precisionmedicinepodcast)*, where experts come to discuss the problems oncologists, reference labs, and payers face as precision medicine grows, and consider solutions for advancing the quality of patient-centered cancer care.*

Jerome Madison: Welcome to the Precision Medicine Podcast. I'm Jerome Madison, host of the Precision Medicine Podcast, and today I have Brad Power, whom I met at the Personalized Medicine Conference at Harvard Medical School, and whom I've come to know as a courageous voice who is fighting for greater access to precision medicine in clinical practice. Brad is a journalist who has authored over 75 articles for the Harvard Business Review, and recently hosted an article on the PMC titled, *Accelerating Personalization in Cancer Treatment: A Patient's Perspective.* You certainly want to go read that for yourself, but he's been gracious enough to come on the podcast and talk more about that.

 Brad, thank you for being a guest on the Precision Medicine Podcast.

Brad Power: My pleasure. It's an honor.

Jerome Madison: Absolutely.

 Tell us a little bit about your background as a journalist and your area of specialty, which is process re-engineering.

Brad Power: Well, my background is actually as a consultant first before I was a journalist. I was at a consulting firm. Discovered in the early '90s this approach, which was a management fad at the time, called business re-engineering or business process re-engineering, which was how to use technology to radically change the way work was done. And it's really a story of transformation, of getting people to adopt a better way of operating. And I was already looking—before my diagnosis in July of lymphoma—I was already looking at personalization as it applies to healthcare, and particularly cancer treatment. And then with my diagnosis it sort of caused me to focus even more so on this, so that I've made it my purpose and mission to help people with a cancer diagnosis navigate to the best options for their treatment.

Jerome Madison: I learned when we came in contact, I learned…and well I guess an entire room of doctors, scientists, and healthcare professionals learned…at the PMC Conference that you had been diagnosed with lymphoma, and you were being treated for cancer. Do you mind telling us about your diagnosis, and where are you in your treatment journey today?

Brad Power: Yeah, so I experienced very extreme belly pain in July and went to an emergency room and was expecting ... it could have been one of a hundred things…but when the stern-faced doctor in the emergency room came to me and said, we've looked at the CT scan and you have lymphoma, that was not what I was expecting. So-

Jerome Madison: Jeez.

Brad Power: It sort of just ... Like I guess with many people it just opened up a whole learning curve and experience start for a whole new part of my life. Figuring out what that meant. What is lymphoma? What is that disease? And, what are the treatment options? And, what do I do? I was very fortunate in that I was at an alumni camp in California at lake Tahoe, and among my friends at this camp was an oncologist at Stanford. And he was able to say, okay, what you have is kind of tried and true and a standard thing, and we have a treatment for it. I'll see you again in a year. So I went into it with a very positive attitude that I was going to come through it, just like you would come through a surgery or anything else and be fine in the end.

Jerome Madison: Yeah.

 When you have that experience ... I guess we'd never have an expectation of getting that news, but in hindsight you have the very optimistic view of your friend from Stanford who would use that as a bedside manner versus the very stern-faced physician there. What is that experience like, and what do you expect doctors should be able to do when delivering news like that?

Brad Power: Well, I'm a very unusual, emotionally stable person. I'm sort of like Dr. Spock from Star Trek. I grew up playing cards, I played a lot of bridge, and you're dealt a hand and you just ... if you're dealt that card you just play good defense. I was also an athlete. You don't complain about referees calls, you just play the game the best you can. So, I kind of went into it ... When I got the news the stern-faced doctor thought that I would collapse, and I imagine a lot of people do, but, no. My immediate thought was, okay, that's the news, now what do I do?

 And it was only subsequently in talking with a friend of mine, who's written an article for the Harvard Business Review about resiliency, who was coaching me ... and he became a paraplegic just over night, and he's been confined to a wheelchair for the last 15 years. And it was completely out of the blue, completely random, but he said that he and his wife have decided that this was meant to be. And it gave him access to things, as someone in a wheelchair, that he would not have had otherwise. And so I said, ooh, that's a challenge for me. I have to find the positive side. So, this is a win, this is an advantage, this is an asset. This is something that's going to help me.

 And so I challenged myself to try to figure that out, and I did. And it actually came true at the Personalized Medicine Coalition Conference that you referenced, that I stood up and—we can go into the situation—but I found that by expressing my perspective as a patient that I got a lot of people saying, I appreciate what you shared, I valued what you shared, please do more of that. And I got this first experience that, because I was looking at my cancer diagnosis as a positive, it had that kind of effect, and I could feel really good about it.

Jerome Madison: And you used your voice in a very powerful way in this instance that we're talking about. And to give the listeners a little context here, in the article that you wrote on Personalized Medicine Coalition you actually detailed the experience you had at the conference when you heard a leader from a very prominent cancer center in Boston talking about what they do, how they practice precision medicine, in a way that was, hey, we're the leaders in this, we sequence everyone, everyone else should follow our lead. Can you share what that experience was like, how his words resonated inside of you? And then, what inspired you to get up and then speak back to him in front of this audience, this auditorium full of people?

Brad Power: Well, I assume that we shouldn't use swear words on your podcast, but what ran through my mind was, I'll use the abbreviation, was BS. And so I was, gee, that's not been my experience. I know that institution, and I have deep respect for it, it's where I'm getting treated. I consulted to them a decade ago, but that's not been my experience.

 So, I went up—and you have to visualize this auditorium with two aisles and microphones, and he's at one microphone—so, I go to the opposite microphone, I'm recognized by the panel, and say, “Look at me, here's my bald head. That's because I'm getting chemotherapy at your institution. I deeply respect it, I respect you. I'm sure what you're saying is true in terms of strategy and policy, but just parenthetically for you and me, and given my experience consulting in large organizations, I know that what executives say and what actually happens at the frontline…there's often a breakdown somewhere in there. And I just want to tell you that it's not happening at the frontline, that I have not gotten my tumor sequenced. I've asked my oncologist three times to do so, and, that was the end of July and today is February, I have yet to receive that sequencing as yet. When I last saw my oncologist, he said that it was in the next batch. When I asked when it might be done, he couldn't give me an answer.”

 And I understand why that ... in my case in particular it's not urgent, so it's not gonna influence treatment tomorrow, so it's not something that's holding anything up. But nevertheless, it was an obvious break from what that individual was saying. And I should hasten to say I went up to him afterwards and apologized and said, I didn't mean any disrespect. And he said, he said he very much appreciated what I had said, and that he was frustrated because what they established as a policy in the senior leadership of that institution doesn't necessarily go down to the behavior and practice of every individual doctor.

Jerome Madison: It was certainly a moment, that's for sure, that everybody recognized, that it turned into a moment for him as well because he showed his frustration. Whether that's good, bad, or indifferent, it was a moment. And the respect factor that you spoke about, it was a moment that made everyone in there– because this was an auditorium full of forward-thinkers, early adopters, innovators in the space–and here you have someone in the capacity, who's there as a journalist, but is literally getting treatment for the disease, and really wants this, and in an instant showed that we're not where we think we are. And on your blog, you raised the question, or the discussion, of whether precision medicine is more hype, meaning promise, versus reality. What's actually being done or not done in practice. From your perspective, where are we in the processes of translating gene-sequencing technology into clinical practice?

Brad Power: Well it's certainly in its infancy, I think everybody would agree with that. There is some data that I've been trying to gather, and I don't know if you've had people on your podcast with these figures. In round numbers, if you look at the number of people that are getting sequenced it's small single digits. If you look at the number of people that are getting a therapy based on that sequencing it's about half that, so smaller single digits. So it might be 8 to 10% are getting sequenced, and maybe 3 or 4% are getting a therapy based on that sequencing today. That against the potential, which I think would be far higher than that.

 So, for me, this is a classic case of what we call business re-engineering. Here's a better process, getting genetic information on an individual and then using therapies based on that information. If that's the best practice it's not getting executed in actual to the extent of the promise.

Jerome Madison: We hear the term precision medicine, it's been on the front page of Time Magazine or Newsweek or ... the common magazines that the general population would read. It's even in Grey's Anatomy, they're talking about precision medicine, so it's quickly becoming a public conversation. But as a patient, what's the expectation that you have of a medical oncologist to understand and utilize precision medicine in clinical practice?

Brad Power: Well, I guess I was a little bit dangerous coming into this. I had been researching precision medicine for a couple of years before I was diagnosed, and so I knew the promise of some of these technologies, both on the diagnostic side in terms of getting more genetic information that could target therapies, and then the explosion of new therapies that are molecular, cellular, immunotherapy-targeted types of therapies, and that there's an opportunity to be matching those. And then my experience in getting into the system, I experienced firsthand the conservatism, the focus on the tried and true. Whether that's from the standard of care as what's generally accepted as evidence-based medicine, or whether it's the reimbursement for those therapies, that if it's more cutting edge then it hasn't been proven, therefore it's not reimbursed, or whether it's regulatory or other limitations. The system, because of the do-no-harm bias, which is a very, and safety, it's a very reasonable, and we would want that in the system, nevertheless it does mean that it's very hard to get new therapies introduced.

Jerome Madison: Right.

 In your article you identify and breakdown three factors that have slowed the adoption of precision medicine. What are your thoughts about how we can effect change in these particular areas, and we can take them one by one, but the conservatism of healthcare providers, how can we make change in that area?

Brad Power: So, I just spoke to that really. There's a bias in terms of training culture if you want to call it, the Hippocratic Oath, there's a bias, do no harm, and that just ripples through the system. And again, it's not a bad thing, I'm not disagreeing with it. What I look at it though is the pace of change. I'm a process improvement guy, so the process improvement process for healthcare is the randomized clinical trial, peer-reviewed. And so a typical trial of that sort takes five years, 10 years, on that order, so the clock speed, the cycle time on an improvement in the standard of care is five to 10 years.

 If you look at Silicon Valley, where I've done a lot of my work in software and understanding how Amazon and Google do what they do, and they are continuously innovating, they have something called A/B testing. A/B testing is like, does the blue button work better than the red button? If we use this font or this set of words, which works better? That's what I saw in terms of serving up ads in some of the research I did on innovation in ads. So if you're looking at Silicon Valley, which is making changes measured in seconds as they run a test on some software, versus in the healthcare arena it's five to 10 years, how can we go about getting more of those changes at the Silicon Valley-pace rather than at the medical system-pace?

Jerome Madison: Absolutely.

 You also mentioned that patients are not equipped to lead their care, and in that there's many different opinions with physicians about what it means to practice precision medicine. But at least they have tools, at least they have guidelines to guide them to what might be appropriate for a particular patient. The patients don't have that, and they're not aware of what genomic tests or targeted therapies may be out there. How can patients be better equipped to help move along the adoption of precision medicine?

Brad Power: I think it's a really big challenge, because even if you take a more stable area of medical practice, like let's just take diabetes. I have a friend who's working with the AMA on getting people who are pre-diabetic to adopt the practices that are demonstrated to work better and will avoid the very terrible outcomes of diabetes, and yet people won't do what they know they should do. So, you have this problem that until you get a cancer diagnosis you're probably not gonna pay attention to the fact that there's a whole new world of precision medicine. And then once you get the diagnosis, then you have the issue that people may be depressed or there are emotional barriers to absorbing the information or dealing with the information, and then even so they may not have the resources, intellectually or otherwise, to be able to understand.

 I see a lot of barriers to patients both understanding and then becoming an advocate for, which is what I would advocate, for their more active involvement in doing things like requesting that they get sequencing, which, again, as we've observed in actuality is at very low levels.

Jerome Madison: What do you recommend for listeners who may be dealing with a cancer diagnosis, or who know someone, a close friend or loved one, who's dealing with a cancer diagnosis who want the precision medicine approach? How can they prepare themselves or better educate themselves to speak and request to their providers for sequencing?

Brad Power: So Jerome, I've been doing some research. So, this is my special capability as a background…as a journalist is to help try and show people the path that I've been down, through and navigated, with a particular lens on the new providers that are emerging, because these are startups in many cases, who are providing services that are direct-to-consumer to help educate them, to help bring them up to speed. There's the obvious one that people will start with Google searches trying to learn things. I've found that there are a number of startups that are helping people ... in addition to the obvious, through your doctor, through your primary care, through your oncologist, I've found the societies of the various diseases. So, in my case with lymphoma, there's The Leukemia and Lymphoma Society. They have a lot of great resources. American Cancer Society has a lot of great resources. And then there are a lot of startups that are emerging that are helping people educate themselves, and there are also a lot of online resources to connect people.

 One of the things that I would naturally do, and I think many people would want to do, is connect yourself to someone who's been down this road before you. And to be able to get onto an online forum or to find people who have been diagnosed and are several years ahead of you in this treatment, so you can talk peer to peer. Those are all assets and resources that can help people online that, again, probably wouldn't have existed three, five years ago.

Jerome Madison: Thank you for that feedback. It's very valuable.

 At Trapelo we lead the conversation of bringing together payers, laboratories who do the sequencing, and of course the providers, and leading the conversation of how can we provide greater access and scale to precision medicine? And most importantly, how do we pay for it? Because you mentioned also there's a lack of payer reimbursement. What are your thoughts around why and, I guess, how payers should pay for precision medicine tools?

Brad Power: I'm gonna answer a slightly different version of your question, which is, where is the disruption going to come from? So, we know that the system needs to evolve and adapt and be more agile, faster, to this explosion of new possibilities in treatment, and if the payers are getting in the way of reimbursement—which so many people will say we can't do that because we're not gonna get reimbursed for it—even though it might be the best path for a given patient, that's a real challenge. So, if we have to look at where that disruption is going to come from or where the road blocks will be ... Coincidentally, I consulted to one of the large blues, one of the payers, for quite a number of years, and I found them to be very well-intentioned, but also very conservative in the same way that I spoke about the conservatism of providers. They don't change very quickly. And so I'm very pessimistic about the payers proceeding at the pace that's needed to keep up with the explosion and the rapid pace of innovation. So, I'm skeptical there.

 My belief is that pioneering patients—so not all patients, in fact, maybe only a very small percentage of patients, maybe a small, single percentage of patients—is the source of disruption that I am looking for. People that take it upon themselves to become these educated experts and drive the system, maybe even becoming rogue or renegades somehow, and then having success. People who will adopt these new approaches, have success, and become a role model and embarrass their peers into reimbursing for those.

Jerome Madison: Michael Pellini, who was the former CEO of Foundation Medicine, I guess said as much what you're saying, is that patients will force us to figure it out. And Brad, your voice and what you're doing is one of the voices that is bringing a sense of urgency to the conversation of providing greater access to precision medicine, and forcing physicians to really figure it out, of how we can get these tools into routine clinical practice? So, I applaud your efforts, and thank you for your voice and bringing your story forward.

Brad Power: And Jerome, I wanted to thank you for what you're doing with this podcast. I met you at that conference, and I realized that there is no other precision medicine podcast that at least I've found, and I'm trying to come up on a learning curve. And so you're providing a great service, I've enjoyed all of the podcasts you've done so far. So, I want to express my appreciation for what you're doing as well.

Jerome Madison: We are eternally grateful for your good comments, and certainly for the courage to come forward and really speak out about that. So, we appreciate it.

Brad Power: Likewise.

Jerome Madison: So Brad, if there are listeners out there who want to get in touch with you or have you come speak, how do they get in touch with you? Do you have email, social media platforms that they can connect with you?

Brad Power: Thanks, Jerome. I'm, bradfordpower@gmail.com. I've just put up a website, re-engineering cancer treatment, and my bio's on LinkedIn, Brad Power.

Jerome Madison: Awesome.

 We thank Brad Power for coming on and sharing his journey and perspective on precision medicine, and we also thank our listeners for joining us today. We hope that you will tune in for the next episode of the Precision Medicine Podcast. If you see us on LinkedIn please comment, please re-share it. And also don't forget, if you enjoyed this episode you can download full transcripts of today's episode at precisionmedicinepodcast.com. If you enjoyed it, I'm sure you know someone else who would too, so please tell them, because they'll thank you, and so will we.



**About Our Guest: Brad Power**

**Journalist and Advocate for Better Cancer Care**

In July of 2018, Brad was diagnosed with lymphoma and went through a course of chemotherapy. Building on that experience and 35+ years of consulting and research on process innovation and business transformation, he began focusing his professional activities on helping people with a cancer diagnosis navigate to the best options for their treatment.

# Connect + Related Links:

# Email: bradfordpower@gmail.comLinkedIn: Brad Power

# Personalized Medicine Coalition Blog, January 2019: Accelerating Personalization in Cancer Treatment