**EPISODE TEN:**
Leading the Charge: How the Personalized Medicine Coalition (PMC) Promotes Education and Advocacy

Christopher Wells, Vice President of Public Affairs for PMC | March 19, 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, Vice President of Provider Relations for Trapelo and one of the hosts of the Precision Medicine Podcast. Today, we have with us the Vice President of Public Affairs for the Personalized Medicine Coalition, Christopher Wells. Chris, thanks for coming on the podcast.

Chris Wells: Thank you for having me, Jerome. Appreciate it.

Jerome Madison: Now, we met at the PMC Conference at Harvard Medical School. It was, in my opinion, a think-tank of the real, key opinion leaders for personalized medicine. Can you tell us a little bit about the mission of the Personalized Medicine Coalition and the work that you do there?

Chris Wells: Sure. PMC, which is comprised of all of the stakeholders throughout the healthcare system, essentially comes from the assumption that a paradigm shift in medicine will not happen just because the science and new technologies underpinning what we call personalized or precision medicine are rapidly coming into existence—the fact that they hold great promise to improve both patient care and the health system itself. What we do as an educational advocacy and evidence development organization is ,we're focused on ensuring that policies and practices in public and private sectors pave the way for personalized medicine. The mission is to accelerate investment in personalized medicine and encourage its adoption throughout the healthcare system. That's sort of been PMCs reason for existence since it was launched in 2004, and it remains the same today. Although our focus on education and advocacy has expanded a bit to also include evidence development.

Jerome Madison: There was the number of…I was just amazed by the number of, I guess subject matter experts in different fields that came to the conference. Not only clinicians who treat cancer patients every day, but also people who advocate for, as you said, policy for precision medicine on the Hill to investors. When you put together a conference like that, what do you look for to put together the experts on these panels?

Chris Wells: The goal of the conference is to explore the issues in personalized medicine that are surfacing in science, business, and policy. When we put together the conference every year, we're first off looking to tackle those issues. The first step is to identify those issues. PMC is well positioned to do that given that we are a multi-stakeholder organization, as I mentioned, focused on advancing personalized medicine. What we do is first identify the issues facing the field. From there we look for—and actually work with throughout the year—many of the individuals who are attempting to tackle those issues and attempting to solve the challenges that stand in the way of a version of healthcare in which patients and doctors not only talking about what disease the patient has, but also which therapy will be most appropriate for them. Again, it sort of starts with our understanding of what the issues in the field are, and we build from there.

Chris Wells: So, once we have sort of a list of the issues and a description of the panels we want to put together, we ask ourselves the questions, “Who has proposed big ideas in this area? Whose work ... Which organizations’ work are really driving progress in this area?” So, that's sort of how we go about it. Our goal as always with the conference and with the rest of our work is to be inclusive of multiple perspectives so that we will not come up with solutions that are sort of a way to advance one particular group of institutions business model, but that cut across multiple business models and show us the way forward for patients, because they're that the epicenter of everything that we want to do.

Jerome Madison: Certainly. As the Vice President of Public Affairs, as you just mentioned, you have to be well versed in the many different aspects of how we advance precision medicine. What or ... Why are you so passionate about the work that the coalition does? Kind of give us a glimpse of your background and kind of where you came from and going ... coming into the work that you do for the organization today?

Chris Wells: Sure. Well, I'm actually trained as a journalist originally. My undergraduate degree was in journalism. Then I went to a small state school in Upstate New York. Did a degree in journalism and worked in journalism for quite some time. I think, among other things, journalism gave me a relentless sort of focus on learning and extreme intellectual curiosity. After that, I went on to get a master's degree in public administration and did some research in public communications. When I finished that up, I moved to Washington and was looking forward to getting involved in a nonprofit organization with some big ideas that I thought could influence the world and society as we know it. Personalized medicine fits squarely into that criteria that I was sort of looking for. I think what continues to drive my passion for my work, and the reason I want to be here, is that I sincerely believe that the technologies and the science and the therapies that are underpinning personalized medicine are suggesting that we can make healthcare better.

Chris Wells: Again, by having a version of healthcare in which patients and doctors are talking about which therapy is going to work best for that patient and making decisions not only based upon what disease that patient has, but upon who that patient is from a biological standpoint, from a societal standpoint, and from a personal standpoint and emotional standpoint. I believe in the coalition's mission. I believe that it's true that unless we aligned the rest of our health system, our business strategies, our policies with the science, the transition to personalized care is not inevitable.

Chris Wells: Every year, as PMC is shown through 2017, the number of FDA approvals is about 20% of all medicine. Our personalized medicines, It actually exceeds that 20% threshold. It's been that way for the last four years. Our preliminary look at what's going on for 2018 suggests that that trend is going to continue. So, again, recognizing that drugs do not work the same way in every individual and that that's been a fact of medicine for the duration of history, and then we now have an opportunity to answer why and to tailor our health care accordingly. It's safe to say that I don't want to be anywhere else until we are across that finish line and are able to achieve that goal. I'm sort of committed to it for as long as that may take.

Jerome Madison: I know there is a lot of people ... A lot of people who are happy to hear that mission and hear the passion that you have. How old is the organization? How long have you guys been doing this work?

Chris Wells: The coalition was formed in 2004. That year is significant in part because that is a year after the National Institutes of Health completed the first sequencing of an entire human genome. It was formed in 2004 on the heels of that announcement, and on the assumption that information based upon the genome, and now sort of expanding into the proteomics, metabolomics spaces would and has great potential to improve patient care and the health system itself.

Jerome Madison: So, Chris, I started in the, what we call now the precision medicine industry, for the first company that had any type of molecular offering. I'm amazed at how precision medicine has changed in the past three years, let alone the last 15 years. For the conference itself, how has the conference evolved since the beginning, and what has surprised you most since you've been involved?

Chris Wells: The conference actually was started by Partners HealthCare Personalized Medicine, the group at Harvard itself, Healthcare System at Harvard. Its inception coincided with the launch of the Personalized Medicine Coalition. PMC has played a valuable role in the conference for the duration of its existence. But, we began actually taking over all programming for the conference in 2016. I've been involved in that work for the last three years. So, really I think my perspective would be shaped mainly by just three years, which is actually…amazingly it's plenty to see sort of the evolution of where we came from to where we are. I think in terms of what has surprised me the most, it's really been…the answer would be the science. The evolution from where we were even in 2016, where we really weren't thinking about gene editing and some of these other genomic applications like the CAR T-cell therapies that are transforming sort of the conceptions of certain cancers…treating certain cancers.

Chris Wells: Those things were not on our sort of—we were aware of them, but they weren't front and center for our agenda in 2016. You sort of fast forward to now, where we're starting to look at the 2019 agenda, and they're shaping that agenda. They're a key component of everything we do. Another trend that is really transformed that from a scientific perspective would be artificial intelligence. Whereby again, three years ago that was sort of a ... we were aware of it, we were tracking it, but we were not actively incorporating that into everything that we do. But, now we are. Then other trends include things like digital health. But I'd say the science, and in particular the three trends sort of intersecting trends of gene therapy and gene editing, artificial intelligence, and also the rapid development of genomic sequencing technologies would be sort of the three driving forces of the last three years that relates to transform how we look at the conference.

Jerome Madison: This year's conference was titled Preparing For The New Possible. I gotta tell you, it was just well done from the welcome reception that was at the Boston Museum of Fine Arts, which is…great touch by the way.

Chris Wells: That's great. Thank you, Jerome. Really appreciate that feedback.

Jerome Madison: The panels were amazing from artificial intelligence to gene editing that you just talked about. Diversity. You had, my goodness, CEOs of drug companies, venture capitalists, they all came to talk about preparing for the new possibility for the scale and access to precision medicine. But what were some of the big aha moments for you at this conference this year?

Chris Wells: I can sort of share ... I think as I do, I prepare the conference materials and been responsible for the conference content. It's sort of amazing to see from the perspective of when I'm sitting in the audience what comes up as the key concepts. I sort of would like to list a few of them. During the second day of the conference, Peter June, who's from…he's the global head of value-based partnerships at Amgen…noted that we have science and medicine and technologies that are far outpacing a structure that was set up in a completely different era. I remember when he said that, that really clicked to me, and everything we had been talking about leading up to the conference and during the conference was sort of his remarks gave us a framework within which we could put all of that.

Chris Wells: So, that was one sort of important aha moment. I think that really there is some trends, sort of some themes that came out of all of the discussions that I would highlight. The first of which that the pharmaceutical industry is increasingly developing personalized therapies. That's in large part because they offer a transformational benefit that traditional therapies can't do. I was impressed upon by Daniel O'Day, the CEO of Roche comments that, that this is the case. If you target the population it improves the transformational benefit of the medicine. So, that was key. Another takeaway message was that I was really impressed and excited and motivated by the patients who noted that they're concerned that the field cannot move fast enough, and sort of those are the people who are waiting for what we're trying to do.

Chris Wells: That was I think, a theme that really became essential to the rest of the conversations. Other things that we learned, I think, are the barriers, especially in diagnostics, which are essentially the linchpin of everything we want to do in personalized medicine. The barriers have to do with policies as opposed to the science. A lot of the people there sort of were amazed at the scientific opportunities, but more discouraged at—or perhaps not discouraged, but more focused on improving the policy landscape so that those technologies can get to patients. I was impressed upon by that and that was an important takeaway. Sort of the last two concepts that really stood out when I think about this question, the idea of evidence generation. We have to be able to generate evidence that demonstrates that this stuff works and that personalized care has clinical and economic utility.

Chris Wells: That really, I think, was shining loud and clear at the conference. Then finally, the last thing I would highlight is the reimbursement question. I found that to be an important part of the dialogue. Again, all of these things sort of wrap neatly into the idea that the health system that we have is not prepared for the science that is emerging. It just really spoke loud and clear as the conference kind of… each of those topics were brought to light. That each of them were in tension with the health system itself. The science is colliding with a system that is sort of one size fits all still.

Jerome Madison: For those who are out there listening, how can they get in touch with you? Can they connect with you on LinkedIn, or is there a website where they can go to learn more about the Personalized Medicine Coalition and also the conference that's coming up in 2019?

Chris Wells: The domain names for both are pretty simple. It's personalizedmedicinecoalition.org. That's our organization's website. We do have contact information in the about section of that website through which somebody could email us for more information. Then, in terms of the conference itself, it's personalizedmedicineconference.org. We're trying to keep things simple and accessible for people.

Jerome Madison: Absolutely. You mentioned that the takeaway, the undertone of all of these conversations was how can we get insurance companies to routinely pay for them? To, number one, allow precision medicine to grow. To allow the uptake and access for patients. Also to spawn innovation, because the diagnostic testing to find the aberrations or find mutations are the linchpin that's going to enable precision medicine. We spoke about it, but what are some of the your ideas of how and why payers should reimburse for genomic testing?

Chris Wells: When it comes to reimbursement for genomic testing, we essentially are focused on that evidence development piece, which I sort of mentioned at the top half of our conversation. We recognize that what payers messages are to diagnostic companies in most cases is that you don't have enough evidence to convince us that we can in good faith spend our resources on this and get a good return for patients and the health system. What we've done—and what we believe is extremely important to continue doing—is to commission studies that will examine those questions of clinical and economic utility. We've developed payer advisory committees that we share the results with them and discuss the process by which we're commissioning these studies throughout the project, so that we might demonstrate to them or provide evidence that in…especially in…areas of care where we know personalized medicine can have an impact such as non-small cell lung cancer or rare disease.

Chris Wells: Those are the two areas we're focusing on. We commissioned a study a year ago in non-small cell lung cancer. What we essentially found is that actually next-generation sequencing specifically that kind of genomic sequencing in non-small cell lung cancer does have moderate cost-effectiveness. More importantly, and this was the real finding of this study, is that it would have a lot more clinical and economic utility if there was not what we call a practice gap, meaning that there are times in which the test results suggest a patient should get a certain targeted therapy, and the patient never got that targeted therapy. As a result of that downstream challenge, the test, the data suggest that the test is not clinically and economically useful in the way that it would be if the practice had aligned with the recommendations made in the test.

Chris Wells: For us, that's a key finding, because we understand that the test is only part of the equation and what's being done with the information is a big part of what personalized medicine is. So we were able to highlight that in this study. We believe that that's really important for payers to understand as they go into these conversations about reimbursing genomic testing. That's one of our efforts. Then, this year, we're looking to commission another study on whole-exome sequencing and undiagnosed disease, whereby perhaps a newborn or somebody is born with a clear disease, but they're not…doctors are not certain what that disease is. In many cases, these patients go through what people refer to as a diagnostic odyssey through which they are receiving care in many cases and receiving incorrect diagnoses and sort of incurring costs without feeling better, without treating the cause of the disease.

Chris Wells: So, one of the more promising areas for personalized medicine would be to use whole-exome sequencing or other kinds of more comprehensive genomic sequencing at the front end of that patient's life, so that one could identify faster what the actual problem is that they're facing and how we can intervene to sort of improve it. So, really all of it falls into that bucket of evidence development. We believe that that's a key driver of these conversations and catalysts for conversations about reimbursement for genomic testing that are more informed and more productive, because, at the end of the day, we meet very few people who say they prefer care that is not personalized. But we meet many people who say we're just not there yet when it comes to a reimbursement standpoint. So, we were very, very focused on that issue.

Jerome Madison: Well Chris, I got to tell you. You certainly help us sing our song. We're trying to get a choir of voices to raise the awareness of the payers. One of the places that this is happening…that payers are coming to talk with Pharma companies, that they're coming to talk to patients and also genomic testing companies is the Personalized Medicine Conference.

Jerome Madison: Chris Wells, Vice President of Public Affairs for the Personalized Medicine Coalition, thank you for being on the podcast.

Chris Wells: Thank you, Jerome. Appreciate it.

Jerome Madison: We want to thank Chris for being on the Precision Medicine Podcast, and of course, thank all of our listeners for joining us today. We hope you'll tune in for the next episode of The Precision Medicine Podcast, and don't forget you can download full transcripts of today's episode at precisionmedicinepodcast.com. If you enjoyed this episode, you probably know someone else who would, too. So please tell ‘em. They'll thank you, and so we'll we.



**About Our Guest**

**Chris Wells, M.P.A. Vice President of Public Affairs for the Personalized Medicine Coalition**

As Vice President of Public Affairs, Wells oversees the development of PMC's marketing and communications messages and leverages a comprehensive portfolio of digital and traditional communications tools to increase awareness and understanding of personalized medicine in the United States and internationally. He also oversees content development for the Annual Personalized Medicine Conference at Harvard Medical School.

Prior to joining PMC, Wells worked as a research assistant at Binghamton University, where he graduated with a master's degree in public administration and received the University's Department of Public Administration Alpha Student Award. He holds a B.A. from the State University of New York at Brockport, where he was honored with Department Scholar's Awards in both journalism and international studies.

Get in touch with Chris Wells

cwells@personalizedmedicinecoalition.org

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