Can Precision Medicine Be a Win-Win for All Stakeholders? Dr. Edward Abrahams of The PMC Believes It’s Possible

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Karan Cushman: Welcome to the [*The Precision Medicine Podcast*](https://www.interventioninsights.com/precisionmedicinepodcast), sponsored by Trapelo. This is the podcast 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. Be sure to subscribe at precisionmedicinepodcast.com to get the latest episodes delivered straight to your inbox.

Jerome Madison: Thank you for joining us for another episode of the Precision Medicine Podcast. I'm Jerome Madison. Today we have Edward Abrahams, the president of the Personalized Medicine Coalition. The PMC represents the precision medicine community, which includes innovators, scientists, patients, providers, payers. Edward Abrahams, thank you for joining us on the Precision Medicine Podcast.

Dr. Abrahams: Well, thank you for having me. I'm looking forward to the interview.

Jerome Madison: Absolutely. We met before, Karan, our producer, and I attended your conference, the Personalized Medicine Conference that you have each year at the Harvard Medical School. Before we get into a lot of questions about your op-ed that you wrote in STAT News, tell us about your background and how the vision to create the PMC was birthed.

Dr. Abrahams: The Personalized Medicine Coalition was created in 2003, just after the human genome had been mapped. It's based on the assumption that the science alone wasn't going to lead to a paradigm change in the way medicine is developed and delivered. We estimated that we had to pay close attention to the space between the science and the patient if personalized medicine was to replace one-size-fits-all, trial-and-error medicine. Back in 2003, a group of institutions across the spectrum of healthcare came together and said, what do we need to do to make this happen more quickly than it might otherwise? They decided then to focus on things like regulation, reimbursement, incentives, privacy, and other public policy challenges that could either stifle or stimulate the development of personalized medicine.

Dr. Abrahams: Since that time, we have grown from the original 20 members to today we're over 220. We have an active agenda that focuses really on three things: raising the profile of personalized medicine and the knowledge that most Americans have never heard of it and don't understand it. Second, creating a friendlier economic and political environment for its development. Finally, developing the evidence for providers and payers that personalized medicine works and can help address many of the problems we face in our healthcare system. It's been an interesting ride over these past 15 years.

Jerome Madison: I see that the PMC, my experience was, it's very much a think tank that promote the understanding and adoption of personalized medicine concepts. Back when you mentioned…when you started in 2003, 2004, personalized medicine in large part was a concept. There weren’t many targeted therapies. There weren't many tests that really helped them facilitate ways to personalize medicine, especially for cancer patients. Over that time, how has the conversation changed from when you started talking about it as a concept—and today it's still a concept to many patients—but how has the conversation been able to change?

Dr. Abrahams: Well, I think that's a great question. Of course, as you know, there has been remarkable evolutionary progress, especially in the number of therapies that are personalized. For example, last year, 42% of all the drugs the FDA approved were personalized medicines. That is, they have biomarker strategies in their labels. You're right, it is a concept. The idea that we're going to move from one-size-fits-all to one that's targeted to patients based upon their molecular profiles is still more a challenge than a reality. Although, as I just noted, and as you noted in your question, there are many, many more examples today than there were 15 years ago of where, especially in oncology, where medicine is targeted based upon a patient's molecular profile.

Dr. Abrahams: I should also add that our definition of personalized medicine includes the patient's values, circumstances, and history. When you bring all these things together, you can get personalized medicine. If I may say so, this is what most patients want.

Jerome Madison: We know exactly what you're saying with the evolution of the concept into concrete therapies, into real tests that can help physicians select or deselect treatments that are likely to benefit the patient or not. On that point, many voices that are looking at this industry are talking about how expensive the drugs are. You wrote an editorial in STAT News because President Trump announced he's going to issue an executive order to lower the cost of the drugs that at least the government pays for to a preferred nation status. He goes on and talks about how other countries are paying less for the same drugs that we do here in the states. You wrote a pretty compelling editorial in STAT News in response to that. I guess the first question I have is, I guess, why do patients in the US pay more? Because I guess he's not wrong.

Dr. Abrahams: That's true, but I don't think that President Trump or congressional leaders who are thinking about how to lower pharmaceutical prices are thinking also about personalized medicine. I think they're assuming that the progress that we have had and that we anticipate is going to happen no matter what they do. Our contention is, of course, they need to pay attention to the unintended consequences of, say, tying pharmaceutical prices to the lowest price in Europe without thinking through exactly what that would mean.

Dr. Abrahams: To your question of do US patients pay more for drugs, yes, they do. The reason for that is that we are alone in the world and not negotiating prices with a governmental entity. As a matter of fact, Medicare prohibits that in the United States. Many feel that we shouldn't pay more for our medicines than say other developed countries in Europe. The problem is, or the challenge is, by so doing, we preserve innovation in the United States, and we also make access to new medicines more likely to happen here than elsewhere. Finally, we've also developed an extraordinarily strong pharmaceutical industry, which benefits patients in the long run. These are the conundrums that President Trump wants to address. My fear is of course he's using a sledgehammer when a scalpel would be the recommended instrument.

Jerome Madison: When talking about that, like you said, there are many ramifications of just going in and slashing cost of drugs. What would this policy, if it were to be enacted, have? What impact would it have on the personalized medicine industry?

Dr. Abrahams: Well, we fear that it could ... Not to be melodramatic about it, but wipe it out, because it would push the pharmaceutical industry back into a paradigm where one size fits all, and they would seek then to develop, as they did in the past, drugs that would fit for everybody. You can hope to sell one to everybody on the planet, even though the science has pushed us away from that. There are diminishing returns in the past ten years developing innovative products that address unmet medical needs. We're moving ... because we're following the science, which is based upon an understanding of individual variation in a particular direction. If we employ some of these policies that have been recommended, we're not going to have access to the medicines of the future.

Dr. Abrahams: You noted that in the public mind, personalized medicines are likely to cost more. That is more or less true. However, what we contend is because they're also more effective and because they're also targeted at smaller populations, they will serve the purpose of making medicine more efficient, which over time will reduce cost because paying for medicines that don't work, which we do now because we prescribe the same thing to everybody, they need it or not, whether it's good for them or not, there are deep costs in doing that. The goal here, the goal of personalized medicine is to provide better clinical outcomes and make the system more efficient. That's what we believe policymakers should keep their eye on.

Dr. Abrahams: I'd be the first to argue that this is an afterthought in the current debate. One of the goals of the Personalized Medicine Coalition is to raise this in the public mind so that we would consider the implications of doing dumb stuff. I think that's what President Obama said. Don't do dumb stuff.

Jerome Madison: Don't do dumb stuff. It is poignant and profound, even though a few words. I'll never forget the words of Dan Von Hoff years ago when he was talking about precision medicine coming forward. He said the most expensive drug is the one that doesn't work.

Dr. Abrahams: That's right. I didn't know that was attributed to Dan, but that's exactly right.

Jerome Madison: That's where I've heard it. In that point though, many politicians and of course payers focus on the sticker price of these targeted agents, these immunotherapies for shock value, but you make an interesting point in your editorial about the cost of not having these innovative therapies. There is a perfect example that you mentioned, a drug indicated for spinal muscular atrophy for an example. Tell us a little bit more about that.

Dr. Abrahams: Well, up until six months ago, this drug didn't exist, and it treats 25,000 patients who have terrible muscular illness where their muscles decay over a short amount of time. With a gene therapy, we can arrest that, and these children can live normal lives. The cost, the sticker cost of that drug is very high, at over $2 million, which is scary for payers and anybody who looks at it. They tend to overlook the value of the drug. Our argument is look at the value and consider the cost that will not occur because the drug exists, meaning the downstream cost of treating the illness ineffectively. It is estimated that cost is over $5 million. When you put these things together, you're looking at a value proposition. Our view is if we want more drugs like that, we cannot dis-incentivize their development by focusing exclusively on cost and overlooking value.

Jerome Madison: Some of the narrative has been over the years that it's expensive to treat these diseases, inpatient, outpatient services, the comorbidities that may occur. In this particular case, for this targeted gene therapy, this is a cure. It's over $2 million but it's a cure. Exactly what you mentioned. If you treat the disease for these particular babies who are born with this gene defect, if they live beyond five years, you're in for over $5 million of treatment and still being affected by the disease.

Dr. Abrahams: That's right. Also, it's important to note that cell and gene therapies are in their infancy. You wouldn't want to do anything to stifle their development at a critical moment. We really need to be careful about what kind of policies we put in place right now and should avoid the hysteria that I'm afraid has affected both Democrats and Republicans about the cost of pharmaceutical prices, which is more related to the insurance issue than it is to the advertised cost of drugs.

Jerome Madison: The PMC is located in Washington DC. Do you guys advocate on the Hill for policy?

Dr. Abrahams: Yes. Thank you, Jerome Madison. As a matter of fact, we're organizing as we speak a personalized medicine caucus on Capitol Hill, which will be a fount of information about these and other issues. There is a great deal of interest in personalized medicine. I just think the issue is that not many people truly understand its revolutionary implications and how it can reshape medicine in the future. If they did understand it, they'd be more supportive. We're working hard to raise the profile of personalized or precision medicine. One of the ways we're doing that is to organize this caucus on Capitol Hill.

Jerome Madison: We hope that helps shape the conversation about how we value precision medicine diagnostics because it's the circular argument for years. The payers wouldn't pay for the testing. Without the testing, you can't accurately customize or personalize therapy without that information.

Dr. Abrahams: The testing is relatively inexpensive, but without the evidence of its clinical and economic utility, payers don't want to pay for it, and so it's expensive to develop that evidence, but it is necessary. That's one of the things that the Personalized Medicine Coalition argues for.

Jerome Madison: You mentioned in the editorial that we need better methodologies for assessing the value of precision medicine diagnostics. What would be an example or an idea of that?

Dr. Abrahams: Our concern is some of the value assessments are static. That is, they don't look at the drug over time nor do they consider individual variation. That is to say that the drug or the therapy that they're evaluating will have differential response across a population. If you use a population average as NICE usually does in the UK, you're likely to not want to pay for medicines that are targeted at subpopulations, and, therefore, may cost more but be more effective. We think the value assessment frameworks need to be much more sophisticated than they are. We are proponents of using them because otherwise, there would be little way to evaluate the value of innovative new medicines. I think that's very important.

Jerome Madison: The work you guys do at the PMC is very unique and extremely impactful. If there is a leader who can shape that, it's you. You do have your Ph.D. You've done work in politics and in fundraising and academic centers. My goodness, Ed. Tell me about your background. What did you get your Ph.D. in and how did you evolve to shaping policy?

Dr. Abrahams: Thanks for the question. My background is in public policy and public affairs. I had worked on Capitol Hill for about ten years in science policy and health care, etc. This was a natural evolution to want to create something new that didn't exist. That's what PMC actually is. I hasten to add we're not a trade association. We represent multiple business models, unlike trade associations, and we want to create something that's innovative and that works especially for patients. Our contention is that we have to share value across the healthcare spectrum that have to create what we consider win-win situations rather than a zero-sum game that so often characterizes how Washington works. That is to say, the payers win, the manufacturers lose. We don't look at it like that.

Dr. Abrahams: We want the manufacturers and the payers and providers to come together to do what's right, to move us from one size fits all to one where medicines are targeted to whom they will work. What's interesting is the science is pointing us in this direction. The science, as many people, including Scott Gottlieb, had noted has never been more promising. Our contention is don't do dumb stuff.

Jerome Madison: Well, I'd tell you. You guys speak about collaboration. We here at Trapelo want to lead the conversation on how payers, providers, and, of course, laboratories can come together.

Dr. Abrahams: Well, Jerome Madison, I think you have led the conversation, and my hats off to you for organizing these podcasts and providing leaders an opportunity to share their views. I'm hopeful that many people, including you, will join us at Harvard Medical School in mid-November when we will think about all of these issues and try to pose solutions to them.

Jerome Madison: I know I'll be there. For those listeners out there who are taking this in, how can they get connected to the PMC? How can they find more information about the Personalized Medicine Conference?

Dr. Abrahams: Our website is personalizedmedicinecoalition.org. You can access our conference there and learn more about us. I would also say that if you'd like to join, please connect to me via the website, and I would welcome a conversation about your needs and how we can help.

Jerome Madison: As always, you can look on the page at precisionmedicinepodcast.com, and we'll have those links to not only the op-ed that Edward Abrahams wrote on STAT News, but also information to get connected to the PMC and the conference.

Dr. Abrahams: Well, thank you very much, Jerome Madison. I really appreciate this opportunity.

Jerome Madison: Absolutely. Thank you for coming on and sharing with us.

Karen Cushman: They can also listen to Christopher Wells' episode on the podcast as well.

Jerome Madison: Okay, so thank you, Karen. We connected with Chris. He did a phenomenal job of welcoming us and orienting us to the conference. He came on and was a guest early on when we launched. We thank all you guys for all the work you've done and for helping us build this podcast.

Dr. Abrahams: Well, thank you. You're a very important part of our coalition.

Jerome Madison: Absolutely. Thank you for coming on and sharing with us on the Precision Medicine Podcast.

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**About Our Guest: Edward Abrahams Abrahams, Ph.D.**
President, Personalized Medicine Coalition

Edward Abrahams Abrahams, Ph.D., is the President of PMC. Representing innovators, scientists, patients, providers and payers, PMC promotes the understanding and adoption of personalized medicine concepts, services and products for the benefit of patients and the health system. It has grown from its original 18 founding members in 2004 to more than 200 today.

Previously, Dr. Abrahams was the Executive Director of the Pennsylvania Biotechnology Association, where he spearheaded the successful effort that led to the Commonwealth of Pennsylvania’s investment of $200 million to commercialize biotechnology in the state. Earlier, he had been Assistant Vice President for Federal Relations at the University of Pennsylvania and held a senior administrative position at Brown University.

Dr. Abrahams worked for seven years for the U.S. Congress, including as a legislative assistant to Senator Lloyd Bentsen, as an economist for the Joint Economic Committee under the chairmanship of Representative Lee Hamilton, and as a AAAS Congressional Fellow for Representative Edward Abrahams J. Markey.

The author of numerous essays, Dr. Abrahams serves on the editorial board of *Personalized Medicine* and has also taught history and public policy at Brown University and the University of Pennsylvania.