**EPISODE SEVEN:**
Using Education to Overcome Barriers to Implementing
Precision Medicine
Dr. Jeanette McCarthy, MPH, PhD, Precision Medicine Advisors | February 21, 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 at Trapelo, and one of the hosts of the Precision Medicine Podcast, and today, we have Jeanette McCarthy, the genome educator. She's an adjunct associate professor at UCSF, and at the Duke Department of Medicine, co-founder of Precision Medicine Advisors, and she's so gracious to drop by and talk about all the things that she's doing to improve the quality of talent and knowledge in the precision medicine industry.

Jerome Madison: Jeanette, thank you so much for joining us.

Jeanette Mc.: Thanks for having me, Jerome.

Jerome Madison: Tell us a little bit about your academic training and your professional background in the precision medicine industry.

Jeanette Mc.: Well, I'm actually an epidemiologist by training, and I had the great fortune to have as my advisor at UC Berkeley, Dr. Mary-Claire King, founder of the first breast cancer gene. So, I am trained in genetic epidemiology, and was really on a path to begin an industry, and so I started out at Millennium Pharmaceuticals right after graduate school, but then went back into academia most recently at Duke University where I could research on the genetics of complex diseases. But then, I made a decision about seven years ago to take a different direction, and so I left academia and founded Precision Medicine Advisors, really with an aim of educating stakeholders in the field of precision medicine.

Jerome Madison: You know our chief product officer, Russ Ingersoll, also did his training at Berkeley, and he's quite the entrepreneur too. But tell us about your company, Precision Medicine Advisors, and what did you see in the marketplace for your company that you created would solve? And who's your target audience?

Jeanette Mc.: Well, as you know, the whole field of precision medicine, it's really going nowhere unless you have educated physicians, consumers, and other people in this whole ecosystem, and we saw an unmet need there. We really specialize in communicating precision medicine to what I'll call lay professional audiences—people who work in this industry but don't have any scientific background in genetics. So, we take all of the complex information, and we distill it in a way that makes it very acceptable to these people. And I mention health care providers, that's one of our big targets right now, we're doing a big push trying to get into health care systems, and also offer events for random health care providers to join to learn about precision medicine.

Jeanette Mc.: I did do some work with consumers as the editor-in-chief of Genome magazine, which was a fabulous publication and that was a great way to educate consumers, and then also trying to work with some of the other stakeholders, for example people in the insurance industry and others like that. So, our goal is really to educate everybody.

Jerome Madison: There's a huge need, and you just mentioned a lot of different stakeholders in precision medicine. How did you guys start? How did you get that training out there, and what's different about how you deliver that training today?

Jeanette Mc.: Well, really the first foray was a Coursera course that I developed through UCSF. I don't know if you're aware of Coursera and all of the courses that they offer?

Jerome Madison: Absolutely.

Jeanette Mc.: I worked Dr. Bob Nussbaum at UCSF and my colleague Bryce Mendelson there. We put together a seven-hour precision medicine course through Coursera. The first thing we offered it, we had about 13,000 people enrolled. The second time, we had about 7,000 people. The last time we put it out, we had it up continuously now, we've had many thousands of people enroll in that course. So, I knew there was a need for it. But that was purely online, and it wasn't very interactive. Since then, we've changed our online model, and I offer my courses specifically through Precision Medicine Advisors, instead of through Coursera. We do a hybrid online/webinar model, but really the thing that I'm excited about are our live workshops. So, we offer workshops, boot camps, to physicians either attending specific conferences, or we'll come right into their organization and offer a custom workshop.

Jerome Madison: Well, you just mentioned it, so I'll dive into that question. Tell us about that Precision Medicine Workshop that you have coming, and give us what the bigger picture is, how is it structured, and any website and registration information that your listeners can go to.

Jeanette Mc.: We have an upcoming workshop on Saturday, March 16 in La Jolla. It is the day after the Future of Individualized Medicine conference—formerly called the Future of Genomics Medicine Conference—that Eric Topol has been putting on for years. It is the premiere precision medicine conference, in my opinion. And we're doing a one-day boot camp workshop where we cover four practicing healthcare providers, how to implement pharmacogenomic testing, hereditary testing for hereditary cancers and cardiovascular diseases. And enrollment is open right now. Again, it's a full day workshop, it's not your typical conference, where you go and listen to somebody speak about a certain topic. You are digging in, and you are hands-on, doing exercises, working through case studies, interacting with your peers, trying to figure out how you're going to take that information and apply it to your practice the next day. So, you can learn more about that if you visit our website, www.precisionmedicineadvisors.com.

Jerome Madison: Now, is it you teaching the content, or do you have other speakers, or experts that are involved in the program?

Jeanette Mc.: I do the majority of the teaching and leading the exercises, but we also have a panel of healthcare professionals, peers, who have experience implementing these types of tests in their practice, and they will be an active part of the program to be giving you their expertise, their experience with these tests in practice, so you'll have that opportunity to interact with them.

Jerome Madison: Now, precision medicine is spreading into many different specialties outside of cancer—in neurology, cardiovascular disease, neonatal, and even diseases like rheumatoid arthritis, they have genomic or genetic targets in their clinical trials. What specialties does your course include? Does it only focus on oncology, or do you have plans to expand that?

Jeanette Mc.: I cover a number of different topics. The workshop that we're putting on in La Jolla is specifically for the top uses of precision medicine, so it's relevant to primary care providers who may come across hereditary cancer, hereditary cardiovascular, and pharmacogenomics. Those are probably the three main applications that they will see in their practice. But, we also have content that focuses on other specific disease areas and also other applications, like using sequencing whole exome sequencing to diagnose a rare disease in a child. We also have programs where we help physicians talk to their patients about direct-to-consumer testing. So, we've got a lot of different content that we have developed already.

Jerome Madison: One of the things that if you read, depending on who you're following, the term precision medicine is very broad, and you just mentioned Germline, and there is other types of mutations which are somatic mutations. If you don't mind, briefly give us a synopsis on the difference between those terms, genetic versus genomic or hereditary versus acquired mutations, or somatic mutations. Can you give a little explanation on that?

Jeanette Mc.: Well, first of all, the distinction between genetic and genomic—and I use these interchangeably, and people aren't very accurate in the use of these terms—genetic refers to anything having to do with the DNA, with your DNA. As you alluded to, you can have mutations in your DNA that are inherited, in other words they're in your germline, and those are the ones that we're typically talking about when we talk about genetics testing. But you can also have mutations that are acquired in specific cells in your body.

Jeanette Mc.: These, in general, are pretty harmless, unless they occur in a specific gene, whereby it basically takes that cell and turns it into a cancer cell, a cell that's dividing uncontrollably. These somatic, or acquired, mutations would be found in those tumors themselves, so at the DNA-level, cancer is always a genetic disease. It's due to defects in your DNA that cause cancer to develop, and as you know, with Trapelo's work in this space, that testing the tumor itself can give you a lot of great information for targeting therapy.

Jeanette Mc.: That's the difference between the germline and somatic variation, and then genetic and genomic, genomic really refers to looking at all of the DNA in a person's genome, versus focusing maybe on just a specific or a specific genetic path.

Jerome Madison: Thank you for that, I know that'd be very useful for many of our listeners. The conference, give us the date again, and the registration fees for those out there who may be interested.

Jeanette Mc.: The date of the conference is Saturday, March 16, and it's really an all-day event, starting around 8:00 in the morning, ending around 5:30. We do have early-bird pricing available right now, which is depending on if you just want a general registration or what we're offering as well is the ability to get your pharmacogenomic testing done through a partnership with OneOme. They're offering significantly discounted tests for 50 dollars for participants in our conference. Early-bird pricing, which ends February 20, is $450 without the pharmacogenomic testing, $500 with the pharmacogenomic testing. After that, the price does go up pretty significantly to $600 without testing and $650 with testing. If anyone's interested in attending, clearly taking advantage of the early-bird pricing in the next few days is a great idea.

Jerome Madison: Awesome. And this is an annual event, or it semi-annual? Do you have plans to expand across the country?

Jeanette Mc.: We have plans to expand, definitely to expand. We'd like to partner with more conferences who would bring to us—who is eager to learn about precision medicine, but we're also working with several healthcare systems trying to bring these events to their physicians and other healthcare providers. Like I mentioned, we do custom workshops, so if you're part of a healthcare organization and you want to educate your physicians specifically on topics X, Y, and Z, we'll come in, and we'll do that.

Jerome Madison: So, Jeanette, tell us about some of the resources that you have online for someone who's listening and who's interested that they can actually go to now and access.

Jeanette Mc.: We currently have a series, what we call the Essential Precision Medicine Series of online courses that are free. When I say course, I'm talking about really a half hour little segment. In approximately one-and-a-half hours you can learn the basic fundamentals of genomics. What is DNA, what is genetic variation, how is that variation related to disease, and what are the main applications of precision medicine in practice today. That is, again, freely available online open to anybody as we speak.

Jeanette Mc.: We also have on our website a resources page where if you're a practicing healthcare provider, and you want to learn about how to find a genetic test, what are some pharmacogenomics resources, where to find genetic counselors, things like that you can find that on our resources page as well. We have a lot of examples of insurance coverage policies or genetic-test reports and a lot of useful tools.

Jerome Madison: Great. Let's talk about your book. You also wrote a book that is called Precision Medicine, A Guide to Clinical Genomics. How did the idea of writing the book come about, and how has it been received?

Jeanette Mc.: We actually, or I was, approached by a publisher to write such a book, and I think the reason they approached me, and the reason that I wanted to do this book was that if you look at the books that are out there about precision medicine, you generally get these huge tomes. These books that are very dense and packed with so much information that if I were a physician and just wanted to learn the minimum, what is the basic stuff I need to know to practice this? That book was not out there. So, I worked closely with my co-author Bryce Mendelson, who is at Kaiser now but was at UCSF. He's a brilliant medical geneticist, also has the same philosophy about teaching precision medicine, where you don't get into the weeds, you give healthcare providers just exactly what they need to be able to practice and not get into the super-super details.

Jeanette Mc.: That was the genesis of the book, and it's been very well received. I've been told by a number of healthcare providers they keep it on their desk, and they refer to it very often.

Jerome Madison: That's fantastic. You mentioned earlier, and for those of you who want to follow Jeanette at Precision Medicine Advisors, could you give them your website where they can go follow you and the things that you're doing there?

Jeanette Mc.: It's www.precisionmedicineadvisors.com

Jerome Madison: One of your blog posts that I read on your website, you mentioned some of the biggest issues with making the practice of precision medicine routine. What do you see as the major barriers for widespread use of genetic testing in clinical practice?

Jeanette Mc.: It's interesting, physicians and other healthcare providers are really the gatekeepers of precision medicine, so if you can't convince them to use some test, then you're gonna have a really hard time moving the field forward. Based on some surveys that I've done and seen from other people, I see maybe four or five main areas that are impeding the uptake.

Jeanette Mc.: One is awareness, so a lot of physicians don't even know what different types of precision medicine tests are available today, and so how do they get that information? That's a big one.

Jeanette Mc.: A number of them are just still skeptical about whether these tests are any good. As you know, this field is pretty much unregulated, and so you get a lot of tests out there that maybe sound too good to be true, and some of those are, and so they really have a hard time saying, “This is clinically valid test.” So, that's one of the other issues.

Jeanette Mc.: And then, surprisingly, the number one issue that healthcare providers mention is cost. The fact that these tests are generally expensive and not covered by insurance. And so that was kind of surprising for me, because I didn't really think they would be looking out for their patients so much in terms of cost, but they are.

Jeanette Mc.: And then, the last one, and this is something that I really try and address in my work, is a lot of healthcare providers just don't have the confidence to be able to use precision medicine tests in their practice, because they don't have any training in genetics, they don't have the skills, they don't know where to find the tests, how to interpret the results, how to communicate with their patients. So these are the types of things that I really focus on. Giving them the basic genomic literacy and the skills to practice.

Jerome Madison: Okay, I just want to let you know you just really unpacked like a trunk of conversation that we could have a whole separate podcast on, right? You just said a lot, so I don't want to step on these things that you said. Wow.

Jerome Madison: Okay, so, one, the awareness. One of the things—and it just depends who you ask around the country—some people will say, “Oh my gosh, how are people not practicing precision medicine? It's been a conversation for years.” There are other people who'll say, “There's so many reps, there's so many companies, it's just muddied the water as to what's the best test. Everybody talks about the same thing.” How do you feel the growth of the industry, the different commercial labs that are offering precision medicine tools have affected the awareness, the lack of awareness, or just confused or muddied the water? What's your thoughts on that?

Jeanette Mc.: Yeah, even this is a really huge topic to unpack, but I think that, as you alluded to, the testing industry has just exploded since 2013 when the Supreme Court said you couldn't patent DNA anymore. All of a sudden, all of these companies started offering genetic tests, and you have some very reputable companies out there offering great tests. But, you also have some companies out there offering not-so-good tests. And then you layer upon that the whole direct-to-consumer testing, and all of a sudden, physicians have so many choices about which test to use, which companies to use, that it can be overwhelming. And, as I mentioned, not always easy to discern the good tests from the bad. So that, for me, I don't envy the position that they're in.

Jerome Madison: Yeah. And it can certainly have an impact on the confidence factor there to order what from who and at what time. The other thing I wanted to talk about is the cost. Now, Tony Magliocco, who is the chair of anatomic pathology at H. Lee Moffitt Cancer Center, and another podcast guest, has mentioned this. When it comes to clinical diagnostics, the data that they quote or the information is that clinical diagnostics—not necessarily in precision medicine but across the board—accounts for about three percent of healthcare costs, but responsible for 97% of the information to make decisions for patients, And in the case of precision medicine, obviously finding out who's likely to benefit and who's not likely to benefit. It's perplexing that the cost of a good DNA sequence or test out there may be $5,000. It's a number that's been floated for years, since I've been in the industry, for the last 16 years. But the cost of a drug, we hear this at ASCO, the most expensive drug is the one that doesn't work. So how do we reconcile this cost conversation?

Jeanette Mc.: Well, it's a combination of cost and insurance coverage, obviously, right? Because the ultimate cost is what the patient pays. We are seeing costs for some of these tests come down dramatically. You take the hereditary breast cancer test which in 2013 cost $4,000, and today you can get a test that's better, in terms of more genes, you can get that for less than $200. So the costs are coming down to a point where maybe patients are willing to pay out of pocket for this information. But the real key is convincing insurance companies that they should cover some of these tests, and that I think is probably the biggest hurdle. I'm not sure how exactly to tackle that. Of course, they're cautious. They've got a business to run as well, and they want to make sure that the tests are cost-effective and clinically useful. So, we have a lot of work to do proving that through clinical studies, randomized controlled trials, things like that.

Jeanette Mc.: But also, the decision to cover them are sometimes based on guidelines. What does the guideline say? If the guideline says you have to have a family history or you already have to have disease in order for guidelines to recommend having a test, then maybe the insurance company's looking at that and saying “Okay, we're only gonna cover people who have the disease already.” So, until we change the guidelines, too, that cost decision's not going to change.

Jerome Madison: Understood. I always thought, and there's several people talking about that, the X-factor in the growth of precision medicine is going to be the consumer. What role do you think consumers will have in driving precision medicine into practice?

Jeanette Mc.: Well, I think that consumers are becoming much more engaged in their own health, and you see this kind of explosion of direct-to-consumer genetic testing too, so they're aware that there are these tests out there, and they wanna know, “how come I can't get this information?” So, look at a company like 23andMe that's offering pretty much recreational genetic testing, but they have some health-related tests that were cleared by the FDA this year as well. But you've got millions of customers using 23andMe and studies have shown that about a quarter of them actually go to their healthcare provider after they've done this test and say, “Hey, look, I have these genetic test results, what do I do with these?” So, you're going to have more and more physicians…and when I give workshops, I always ask the room. I say, "How many of you healthcare providers have had a patient come to you with their 23andMe results?" And just about every hand goes up.

Jeanette Mc.: So, you have consumers who are educated going to their physicians saying, "help me understand this." So, I think that's a positive force actually where they're really bringing physicians to this point where they need to be educated in order to answer these questions.

Jerome Madison: Yeah. How do you think consumers…what should be available or what could be created to help consumers be better educated to direct and get involved in their care in precision medicine?

Jeanette Mc.: That's a tough one. I mean, the thing that I mentioned—because this whole genetic-testing space is pretty much not regulated right now, because most of these tests are laboratory developed tests and everything—I think that healthcare providers as well as consumers have a hard time knowing what's good and what's not. I don't know the best way to make sure that consumers are only using tests that are good, because there are so many out there. That's definitely an area that I would like to focus on is increasing the education in that group as well.

Jerome Madison: Well, if anybody is the right person to do it, Jeanette, you seem to be, because you are making great strides and really filling a need in the marketplace that no one else is really doing. You have academic centers who do education and conferences but, independent of that, you're really providing a unique service that is very valuable. So, thank you for doing that.

Jeanette Mc.: You're welcome, and thank you for the opportunity to be on this podcast and help spread the word.

Jerome Madison: Absolutely. Absolutely. Jeanette McCarthy, the genome educator. You can find her at www.precisionmedicineadvisors.com. We want to thank all of our listeners for joining us on the Precision Medicine Podcast today. If you liked this episode, I'm sure you'll know someone else who would, so please tell them. Also, you can catch us on Twitter. Our Twitter handle is @PMPbyTrapelo. That's @PMPbyTrapelo. You can find full transcripts on www.precisionmedicinepodcasts.com. Thank you for joining us, and we hope to see you next time.



**About Our Guest: Jeanette McCarthy, MPH, PhD**
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Adjunct Associate Professor, Community and Family Medicine, Duke University
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Jeanette McCarthy is a UC Berkeley trained genetic epidemiologist and spent the early part of her career in industry at Millennium Pharmaceuticals before transitioning to academia. She currently holds adjunct faculty positions at Duke University and UCSF. Her previous research had focused on the genetic underpinnings of complex diseases, both infectious and chronic. More recently, she has become a leading educator in the field of genomic and precision medicine involved in demystifying genomics for non-technical audiences, including health care providers, patients and other stakeholders. In 2014 she helped launch the first consumer-facing magazine in this field, *Genome*, where she served as editor-in-chief until 2016. She teaches genomic and precision medicine through UCSF and UC Berkeley Extension and online through *Coursera* and through the *Precision Medicine Academy* (precisionmedicineacademy.org). She also designs and delivers custom workshops and courses to international audiences and advises companies on strategic and technical aspects of precision medicine. Jeanette is coauthor of the new book, *Precision Medicine: A Guide to Genomics in Clinical Practice* (2016, McGraw Hill Education).

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